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LISTENING TO THE VOICELESS ONES: WOMEN WITH FETAL ALCOHOL SYNDROME AND FETAL ALCOHOL EFFECT

BY

VALERIE J. MASSEY

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Doctor of Philosophy

DEPARTMENT OF ELEMENTARY EDUCATION

Edmonton, Alberta

Spring, 1997

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DEGREE: **DOCTOR OF PHILOSOPHY**

YEAR THIS DEGREE GRANTED: **1997**

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Valerie J. Massey

103 Westridge Road
Edmonton, Alberta
T5T 1B5

April 1/97

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **LISTENING TO THE VOICELESS ONES: WOMEN WITH FETAL ALCOHOL SYNDROME AND FETAL ALCOHOL EFFECT** submitted by **VALERIE J. MASSEY** in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

Dr. J. Blakey (supervisor)

Dr. J. Ellis (supervisor)

Dr. H. Janzen

Dr. L. Stewin

Dr. S. Chard

Dr. S. Weber (external examiner)

Date: March 24 1997

Listening to the Voiceless Ones:

Women with Fetal Alcohol Syndrome and Fetal Alcohol Effect

Abstract

Alcohol is a teratogenic drug which easily crosses the placental barrier, enters the fetal circulatory system, and is associated with a number of adverse effects. These range from fetal/neonatal death to more subtle growth and central nervous system disorders, depending on factors such as the amount, timing, and duration of alcohol consumption, and maternal health. Although human and animal research is ongoing, there are still many questions to be answered about Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE), the diagnoses which cover the broad group of physical, behavioural, and intellectual characteristics appearing in the offspring of women who drink during their pregnancies.

The primary focus of this study was to explore the lives of five women, between the ages of 18 and 30, who had been diagnosed with FAS or FAE. Extensive conversations presented the lives of these women, exploring the intimate, intuitive knowledge of their experiences. Each was an expert in the field of FAS or FAE and could reveal to us things we had not understood or had not seen before, offering a perspective from inside the diagnostic label. It was hoped that FAS and FAE-affected women might provide other intervention strategies which could more meaningfully influence professional practice in the fields of education and clinical psychology. This study also presented a comprehensive review of FAS or FAE in the literature addressing diagnostic criteria, incidence rates, the risk factors associated with maternal

consumption of alcohol, and the common physical, behavioural, intellectual, and emotional characteristics manifested by FAS and FAE-affected individuals through their lifespans.

As a psychologist, I had become accustomed to a certain way of listening to those with whom I worked. As a psychologist/researcher embarking on a process of interpretive inquiry, I became aware of a different way of listening to the FAS and FAE-affected women who, at first, had appeared to have such difficulty articulating their lives. From their stories came themes which revealed their experiences with education, poverty, unemployment, prostitution, alcohol and substance use, sexual abuse, physical health, pregnancy, suicide, isolation, and inequality.

During this process, I learned much about perseverance and patience. I also learned much about myself, leading to an examination of my experiences as a psychologist/researcher. As a piece of research, this inquiry becomes part of the conversation about professionalism, psychological practice, and personal growth.

This thesis is dedicated to my husband Don, and my daughter Ashleigh, who so graciously shared in this work,
and to my parents, Norma and the late Wilfred Gulliford, who taught me to strive for change and to fight complacency.

I also wish to thank the women who shared of themselves in this work. Without their willing participation, this process of uncovering could have never taken place. They are the truly knowledgeable ones.

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CHAPTER ONE

Introduction

My son will forever travel through a moonless night with only the roar of wind for company. Don't talk to him of mountains, of tropical beaches. Don't ask him to swoon at sunrises or marvel at the filter of light through leaves. He's never had time for such things, and he does not believe in them. He may pass by them close enough to touch on either side, but his hands are stretched forward, grasping for balance instead of pleasure. He doesn't wonder where he came from, where he's going. He doesn't ask who he is, or why. Questions are a luxury, the province of those at a distance from the periodic shock of rain. Gravity presses Adam so hard against reality that he doesn't feel the points at which he touches it. A drowning man is not separated from the lust for air by a bridge of thought - he is one with it - and my son, conceived and grown in an ethanol bath, lives each day in the act of drowning. For him, there is no shore.

Dorris, 1989, p. 264

Michael Dorris, the author of this quotation, was the first to write about the realities of Fetal Alcohol Syndrome (FAS) from a personal viewpoint. His perspective was unique in that he wrote as the holder of a Ph. D. in Anthropology, a native American, and as a loving, adoptive single parent who had welcomed Adam, a young FAS-affected child into his family. He became Adam's father long before there was wide-spread understanding of FAS and FAE and he movingly wrote of his struggles to understand his son and of his attempts to educate others about the very real impact of this syndrome on the native American community. His story has become legend within the sphere

of other families touched by this preventable tragedy. Everyone within this circle knows the name, "Dorris", and everyone has shared his pain and frustration. Each family has its own stories of tragedy and defeat - of small triumphs and infinitesimal gains - although no one but Michael Dorris has written about them so clearly and persuasively.

This study proposed to document the reality faced by individuals with FAS or FAE, but from the perspective of the individuals themselves by exploring the commonalities and underlying themes of five young women with FAS or FAE. By presenting their situations, in their own words, these women provided helping professionals with an additional source of information to make effective change on their behalf. Giving each woman an opportunity to present her own story also gave her a forum to discuss what was important to her, in a supportive, nonjudgemental environment.

This study examined the lives of these young women through a series of in-depth interviews. In each interview, each participant shared her life story which was elicited through a series of open-ended questions. As most FAS or FAE-affected individuals function at cognitively and linguistically lower levels than the general population, these questions were more detailed than is common in interview-based phenomenological research. Despite this need for greater specificity, however, the questions were still open-ended and introspective, and based on other scholarly work with marginalized women.

In my initial explorations of alcohol-related birth defects, I discovered

there were still many questions to be answered about Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effect (FAE), the name given to the broad group of physical, behavioural, and intellectual characteristics which appear in the offspring of women who drink during their pregnancies. Despite the incomplete nature of the knowledge base, there had been increased social sensitivity to the potential dangers of maternal drinking during pregnancy and a growing awareness of the presence of FAS and FAE in the community. Clinical diagnosis had become more rigorous and more common. In spite of a limited increase in knowledge, however, those who worked with affected individuals still did not understand the lives of those individuals who bore the diagnostic labels of FAS or FAE. Researchers had not shared their experiences and, for those who were fortunate to be born healthy and intact, they could not begin to understand the difficulties faced by those who had a handicapping condition. Individuals with FAS or FAE, who did not always appear physically different from their non-affected peers, inhabited the shadows of North American communities. They had become the marginalized who, by virtue of their inability to function, lived in situations the non-affected could never know. In addition to the anonymity in which many of those affected with FAS or FAE lived, the little information that had been gathered did not differentiate between the experiences of men and those of women.

In traditional drug and alcohol treatment approaches, for example, intervention came from a model based on men's experiences with alcoholism. Neither women's life experiences nor the influence of female

physiology on addictive behaviour were considered. Most traditional treatment approaches also excluded women who were pregnant or who had young children (Antoniadis & Daulton, 1992). Smith and Coles' study (cited in Alberta Alcohol and Drug Commission, 1993) described several reasons why pregnant women addicted to alcohol and/or substances were even less likely to seek treatment than other groups of women. These included the tremendous stigma attached to being pregnant and alcoholic, the lack of support from family and friends for entering and completing treatment, and the lack of treatment facilities which will accept pregnant and parenting women.

Research efforts to date focussed intently on the lives of infants and young children with FAS or FAE. Any database search revealed numerous texts documenting the processes of diagnosis and intervention between the ages of birth and age five. There was, however, little information about adolescents with this syndrome and even less about adults. Spohr, Willms, and Steinhausen (1994), authors of a study of adolescents with FAS, noted that little is known about the long-term development and outcome of children with FAS. Streissguth (1993) further reported that FAS has long-term consequences and, although the characteristic facial dysmorphology and growth retardation became less pronounced after puberty, the central nervous system (CNS) effects continued on, often with profound implications for independent functioning, adaptive behaviour, mental health functioning, substance/alcohol abuse, and antisocial behaviour. A pattern of repeated pregnancies for affected women was noted as well. Streissguth concluded that secondary psychopathology was a common antecedent for FAS or FAE-

affected individuals unless early diagnosis and intervention occurred. Apart from these few studies, however, there was little information about how the lives of affected individuals played themselves out against the wider backdrop of society. Scholarly work had failed to address the everyday realities faced by individuals who, because of FAS or FAE, did not meet the expectations of others.

Setting The Stage

I have worked as a clinical psychologist for several years. Most of my work lies in the field of assessment for emotional and psychological distress as well as a variety of learning and cognitive difficulties, including learning disabilities, mental handicap, and developmental disability. While my practice was not exclusively for women, my referral sources tended to send women to me, especially those whose cases were seen as singularly problematic. This included women who had been in "the system" for years as well as those who were new to the network of social services and government agencies which serve troubled individuals. In the course of my work over the last four years, I began to notice a disturbing pattern of dysfunction in a group of women whose backgrounds often shared many commonalities and, primary among them, the consumption of alcohol by their birth mothers.

Referring agencies often saw my intervention as the end of the line, the final trick in the bag, the "last kick at the can". There were few other resources after my involvement and the stakes were high. If I could not establish a

reasonable plan of action, my clients might have had few, if any, alternatives. It had often become my job to find the few remaining options for those individuals who had already exhausted the more traditional sources of support.

For most of the women with whom I worked, there were competing agendas to be acknowledged because these women were usually served by more than one community or government agency. Child Welfare, Alberta Family and Social Services, the justice system, and Human Resources Development Canada could have each represented different needs for a single client. One contracting agency might have held one set of expectations, the next might have had another, and the client might not have expected anything. I was required to somehow acknowledge and balance these conflicting expectations and yet satisfy my own need to be positive, supportive, and honest in establishing workable goals. For many of the women with whom I worked, this was a difficult burden.

Each of the women whose stories I presented were referred to me by agencies involved in their ongoing care. Various provincial and federal government departments, nonprofit associations, or adult educational settings played a part in identifying these women as in need of intervention. Every one of these women had also been involved with other helping professionals. Some of these experiences had been positive. Some had not. Most women were very hesitant and some were frankly frightened of what I would do. Most were sure that I would confirm their worst fears about themselves; that they

were stupid, or crazy, or both. In order to help, I had to somehow work through the barriers they had erected around their dreams and their innermost secrets.

With these wary, frightened women, I tried to structure my initial contact with an honest discussion of why they were there and why I was involved. These women were too used to others telling them where to go, who to meet, and what to discuss. I wanted this to be a frank but fair exploration of the events which had led them to my practice. I wanted them to be comfortable enough to tell me things they did not know they knew. I wanted them to feel a sense of control and equality in our relationship. I do not appreciate dishonesty in others and therefore could not be dishonest in hiding the reason for referral or pretending that this was a meeting of two old friends who had nothing to hide from each other. Some of the women I saw did have things to hide. Criminal activities, prostitution, serious alcohol/substance use, neglect or abuse of their children; live-in boyfriends that their social workers did not know about; outstanding warrants; or prison records were all too common for many of these women. They were not accustomed to openness and the process of trust-building was often disconcerting for them. It took all my skill to get each woman to trust, and sometimes, despite my efforts, we could not reach a mutual understanding of what we needed to do together. I am grateful that this did not happen often.

In spite of the initially coercive nature of our first contact, most of these women and I forged a relationship that had seemed to last even past our last

formal meetings. Many of them continued to phone me, or drop in when they were in the vicinity of my office, to chat or to let me know how they were doing. They sometimes called for advice, or if they thought they were being hassled by other professionals who did not understand them. They called me to weep and to rejoice. In their eyes, I somehow changed from being one of "them" to being one of "us".

I did not know that this would happen and I did not know how it happened. In my explorations as a psychologist/researcher, I hoped to understand how this change occurred; how I came to be one of "us". I had been transformed into just another woman with concerns, struggles, and small joys to celebrate. These women had changed me as surely as I had hoped to change them.

Organization

> *And the main thing is the listening. To listen, to understand, to be open, is one and the same.*
>
> Perls, 1959, p. 41.

When I first proposed this study, the primary focus of the research was to interview five women affected with FAS or FAE with a view to articulating their life experiences and their understanding of themselves. The secondary focus was to present each woman's beliefs about forms of intervention that might have been helpful to her at various stages in her life and which might

be effective for other women in similar situations. In addition, I thought each woman's memories of being a student in a formal education system might provide valuable insights to teachers or other professionals who had undoubtedly encountered someone very like at least one of these women, either as a young child, an adolescent, or as an adult learner. It was hoped that this research could open a dialogue with women who were not accustomed to having their voices heard. They had much to share, but saw themselves as having little to offer. As I progressed through this work, however, I began to see that my research was evolving into more than a mere passive reflection of someone else's story. My own story was being reflected. I could not hold up the mirror for these women without seeing my own image looking back at me.

In their struggle to manage the small details of their lives, I saw my own struggle to arrange my life; to cope with the competing demands of my professional, family, and personal roles. It was a question of degrees, to be sure, but I found a commonality in our efforts to decide things for ourselves, separate from what we thought the greater 'Other" was telling us to do. Each of us had absorbed a sense of what it means to be a woman from television shows, movies, magazines, and other aspects of popular culture. And I was one of the lucky ones; I could examine the messages and discard those that did not match my own sense of who I was. These five women did not have the time or the resources to sort out the relevant from the trivial; to find their own truths in the bombardment of expectations. They knew their realities did not match the messages they saw each day. Their inability to find a personal

fit between the expected and the real led them to blame one of the few constants in their lives; their own continual failure. I hoped to provide them with a place to explore their own sense of what was important for them, perhaps different from what they had been told was important. These women needed a place to discuss their own understanding of "fitting in", and to discover their competencies as well as their limitations.

A vital component of the study was a comprehensive psychological assessment conducted by this researcher, in which the five women were diagnosed with FAS or FAE. The assessment included standardized measures of intellectual, academic, and receptive language functioning. Adaptive behaviour and emotional functioning were also assessed. In addition to these measures, a comprehensive personal history was taken (See Appendix A), along with information about the family of origin available through government agencies, hospital/medical records, anecdotal information, and school records, as available.

This clinical assessment provided each woman with an independent confirmation of her strengths and weaknesses. Each of these women could clearly articulate things that they could do and things which gave them continual difficulty although they could not use the "professionalese" which commands respect and guarantees an attentive audience. Each had repeatedly told helping professionals about their personal awareness of competencies and limitations. And each spoke about her feelings of being ignored by those who supposedly knew better than she. Each woman was

unable to secure an audience with those making decisions on her behalf. Each had become voiceless, despite her best efforts. The assessment process gave each woman a platform to express herself once again. She was provided with an attentive audience who had promised to listen and to hear what she said.

This dissertation has been organized into three main components. In the initial section, I discussed the reasons behind my interest in this area and I presented the story of the woman who first drew me into her world. Her story was not the most poignant I had heard and likely not the first time I met a woman with Fetal Alcohol Syndrome, but it was my first contact with someone who made me aware that there were gaps in my professional knowledge. She startled and then challenged me to know more at a time when I thought I knew enough.

The next section presented my search for the knowledge I did not have. It provides a selective review of the literature in Fetal Alcohol Syndrome and Fetal Alcohol Effect. An historical overview of this condition was discussed, along with various systems of diagnosis. Incidence rates and risk factors were also presented. In addition, the existing research on adults and adolescents with FAS or FAE was discussed.

In my search of the literature, I discovered that the conventional ways of searching for knowledge did not meet my needs, or the needs of the women with whom I worked. I realized that I needed a different approach to this gap

in my understanding and I explored other, qualitative ways to seek meaning. A review of hermeneutic research, addressing my need to tie this research to my practice, followed.

From these reflections on my growing awareness and qualitative research flowed a discussion of my particular research methodology. It was integral to my practice, my need for knowledge, and the needs of the women with whom I had worked. It was tied to language, the ability to communicate with another person. Communion, the act of sharing, participation, and fellowship, is what these women lacked. They had words, but no one had listened. They did not listen to themselves, either, and so they continued on to make the same mistakes, the same errors in judgement, without linking their actions to a result. They had become voiceless.

The stories of the four other women in this study followed. Some aspects of their lives mirrored the struggles of the woman who first challenged my smug assumptions about caring, but there were poignant differences as well. Each woman deserved a celebration of who she was, as an individual, rather than as just another woman with FAS or FAE. Each had a story to tell and, in the telling, learned something about the value of being heard and the value of listening to her own voice. Intertwined with each woman's story was my story as a psychologist/researcher. I, too, learned the value of listening and being listened to, of hearing and being heard.

In the telling of their stories, came an awareness of the commonality of

their experiences. I read and re-read each story and found the painful similarities shining through the differences. And, the more I read, the more I found until, in the end, I found myself struggling to keep each face separate.

CHAPTER TWO

Grace's Story

My initial exploration focussed on Grace, one woman with FAS. I first met Grace when she was 30, after I was asked to determine why she was having so much difficulty in a rural upgrading program. I drove to our appointment, not knowing who I would meet, but sure that I had seen her "type" before, adult women with problematic lifestyles who could not cope with the demands of formal learning. This was a situation I thought I understood. I thought I knew the answers to her difficulties, before I had even heard the questions.

Grace had been referred to me after she had been encouraged by her Social Services worker to take upgrading in an outreach program for adults with poor work histories. By enrolling in upgrading, she was helping her social worker to meet the Department's goals of reducing its caseload. She had been in this program for 18 months, attending fairly regularly and trying hard, but she was "...not making progress..." as one of her instructors reported. The head of the upgrading program thought it might be helpful for Grace to have a psychological assessment to determine whether there were any underlying learning difficulties which had so far prevented her from acquiring the skills which had been repeatedly taught for a year and a half.

There were also some questions about Grace's mental health. She

had been involved in a serious suicide attempt and spent four days in the local hospital's psychiatric unit. The program staff were beginning to wonder whether Grace was an appropriate candidate for their services, since she didn't seem to be learning much, in spite of her regular attendance.

According to the agency which contracted my services, my job was to find out what the problem was, and to suggest the strategies to fix it. What the agency was probably hoping was that I would find, once again, that Grace was deemed "unsuitable" for its purposes and their caseworkers could drop her without feeling they had failed. It did not seem to matter as much if Grace felt that she had failed.

I was not prepared for Grace's impact on me as a professional and as a woman. I could not control my reaction to her and she became unforgettable, even though I work with many unforgettable women who slip through my memory at the end of the week or the month because another one is always coming along to take their places. I can still close my eyes and see that little face, covered with grime and tears; thick, cheap, plastic Social Services-issue eyeglasses covering tiny eyes set wide in a tiny skull. Her nose red and raw from weeping and the cold, tip-tilted like Shirley Temple's above an upper lip too long and too narrow. Her hands reaching up to push her heavy glasses; their nails broken, dirty, and deformed. Grace could not flatten her hands on the table; the tendons in her fingers were foreshortened. She was tiny and when she sat at the table, her feet barely touched the floor. She was also unclean and whenever she moved, which was very often, I was

surrounded by an overwhelming aroma of unwashed body and unwashed clothes. Her eyes darted around the room like an animal caught in a trap. She knew there was a door but she also knew she could not use it. She had been summoned "for her own good" and she was frightened. She had been in too many similar situations with other professionals, ready to pass judgment on her as a bad child, bad student, bad parent, or bad wife.

In the face of such fear, I abandoned my preconceptions. Although I still had a job to do, my first task was to hear her story without judgment, to help her find the alternatives of which she did not know. I was trying to dispense hope to someone who was so used to having none; she was as equally ready to dismiss my efforts as others had been to dismiss hers. I tried to find the positive in her story, searching for the sense of survival that allowed Grace to get back up each time she had been knocked down. In finding that, I found my own ability to continue. I could not abandon the telling of Grace's story in the face of her stolid determination to plod on. For a short time, we became fellow marchers, yoked by an unspoken commitment to truth.

Grace taught me a lesson in never giving up. Despite all that had been dealt her, she still soldiered on. Although her determination was primarily fuelled by her inability to formulate consequences and learn from her mistakes, she had a particular dignity which forced those in contact with her to acknowledge her determination. She did not quit when her life became difficult; she did not know how. Unlike Grace, I knew how to quit but, in the face of her quiet strength, I could not. I knew I had to carry her story through

to the end.

I listened to Grace tell her life, although at first her answers to my questions were short. She used one-word answers, "Yes"; "No". Occasionally I made progress and got a three-word answer, "I don't know." I was persistent. "Where did you go to school?", I asked. "Who were your teachers?" "Did you have any special help in school?" "Did you have friends?" And so we began.

Grace shared the details of her life, if not with enthusiasm, then without concern. Once we passed the indefinable barrier which demarcates trust, she told me many things, often without seeming to realize their implications. I was listening to her story and I was likely one of the first.

Grace told me about her schooling. Many intervention strategies, including special education placement, grade retentions, upgrading classes, and life skills programs, had been tried at various stages in her life. These had all failed, usually because those who had tried to help did not appreciate Grace's world view or her understanding of her place within her community. Grace felt that it was her fate to struggle, to be unhappy, and to fail. Any attempts to alter her situation, even in a minuscule way, were filtered through this deeply-held notion of personal inadequacy. Well-meaning individuals did not know the depths of her despair, and, because she could not understand her situation, Grace believed that no one else could.

Grace endured many indignities and outright abuse because she could not meet the expectations of others. Because she was unsuccessful at school and at home, Grace felt that her adoptive parents did not love or support her. Because she did not learn the way most other children did, she did not feel accepted by her teachers and her hazy memories of school were negative. Grace felt she had been unsuccessful as a wife and her husband, who often beat her or subjected her to humiliation, subsequently abandoned her after persuading her to have a tubal ligation. She could not effectively parent her two children alone, and they were taken from her, placed in foster care, and then adopted.

In addition to the loss of her own children, Grace was denied any access to the children of others. In the traumatic period after the break-up of her marriage, she was convicted of the sexual abuse of her own children. When she was taken to the local police station after she was charged, she did not know she could have a lawyer and she could not remember the police informing her of her rights. Grace pled guilty after a lengthy interrogation. The police offered her a deal, admission of guilt for one charge in exchange for dropping four other charges. She took it. To her, this was a bargain. This "bargain" prevented her from any involvement with children, including babysitting, an important source of unreported income. Grace became even less capable of looking after herself.

Grace had been estranged from her adoptive parents for many years because they did not approve of her lifestyle or the men she met. She knew

she did not fit into her adoptive family, because of her problems. She felt she did not fit into mainstream society either, not only because of her lifestyle but also because of her status as an individual of native heritage. She had no recollection of her birth parents, but knew that her mother was native and her father was Metis. She wanted to meet her birth family but did not know how. Grace thought she might find herself in the native community but did not know the information necessary to seek her birthright. She longed for a place where she could be accepted but did not understand what acceptance was.

Because of her employers' expectations that she could easily master new skills, Grace's few attempts at competitive employment were failures. She was fired from one entry-level position for stealing, although she denied this. She was sexually harassed at her next job. She could not work fast enough at another. Grace's ability to survive had therefore often depended on the goodwill of men who were willing to accept the only asset she had, her own body. Although she claimed to have never worked as a prostitute, she likely bargained her body for a warm place to sleep, a meal, or a drink. Her naivete about common social conventions left her open to continued exploitation in her personal life. Her timidity and passivity also made her an easy target for those who prey on the vulnerable.

Grace had no children to care for. She had no husband. She had no friends. She felt she had no parents. She had no community. Grace did not have the vocabulary to articulate the emptiness in her life but knew she was alone.

Despite Grace's extremely weak receptive language skills, she spoke poignantly about her experiences and the losses which punctuated her life. She articulated the realities of an individual who has never felt accepted but who thinks that non-inclusion is what she deserves. She spoke of being a student, a wife, a mother, an employee, a client of the criminal justice system, a woman. She shared all the details of her life with pride, perhaps because no one had ever asked her to share them before. I, who could never watch even witness fantasy pain on a TV show, listened to a real story of real pain from a real person. I could not turn off Grace's "show" just because I was uncomfortable. I was compelled to listen because Grace could not turn off this "show", either. It was how she lived.

I felt someone must bear witness to Grace's existence and present "the marginal and secret [story]" (Steedman, 1987, p. 5) of a woman who lived her life on the outskirts of society. It seemed there was no one else to present Grace's story; to articulate her desires for a better life and her struggles for growth. In trying to understand Grace's story, my story became entwined with hers.

After my initial contact with Grace, the referral agency and I scheduled a meeting, a case conference, to discuss the results. Grace knew that she was to attend, but I also encouraged her to bring someone along for support, if she wished. To my surprise, she brought her adoptive parents; two elderly, gentle people who seemed rather bewildered. Perhaps they were puzzled by Grace's invitation as they had played a peripheral role in their daughter's life

for several years. They had driven about eighty kilometres to attend and it seemed that meetings like these were unhappily familiar to them. After all, they had been part of Grace's sentencing and her parole, and knew all too well that most professionals did not see their daughter as a competent or even likable individual. They huddled in their seats, one on either side of Grace; weary bookends supporting their disintegrating daughter.

I spoke first, addressing my comments to Grace and her family. I talked about the need for honesty and openness, and about my heartfelt desire to help. I encouraged everyone present to feel free to disagree with what I said, to ask questions, or comment whenever they wanted. I told them that I was not an "expert" on Grace or on anything, that others likely knew her much better than I, and that I did not have all the answers. I strove to open an honest dialogue with everyone present about what we all needed to do to help Grace move forward, if that was what she wanted to do.

We discussed Grace's intellectual limitations, her academic difficulties, her problematic emotional reactions, and her poor adaptive functioning. I talked about her inability to manage things on her own and her need for extra support. I also talked about her need for a guardian and trustee to help her live as independently as she was able. We discussed Grace's need for additional support in employment settings and her inability to learn through conventional instructional techniques. I raised the possibility of a special employment training program designed for individuals with limited cognitive and academic skills. It turned out that this program was available in Grace's

parents' home town and she agreed to give this program a try. I also mentioned the possibility of government support, should it happen that Grace was unable to secure employment in the competitive labour market. These were options that Grace and her family had not been offered before.

During our meeting, I asked Grace's parents if they knew anything about Grace's birth mother. From their expressions, it was clear that this was something they had never mentioned in Grace's presence. Grace's father said that his daughter's birth mother was a well-known alcoholic and "a woman of the streets", to use his delicate phrasing. She had died shortly after Grace's birth and, although they did not actually know the cause of her death, they speculated she might have died in a fight or because of alcoholism. They also knew that Grace's birth father was an alcoholic and that Grace was apprehended because she had been inadequately cared for.

Her adoptive parents thought they had tried their best, and they likely had. They told of hours of flashcard drills, first to help Grace learn to read, and then to retain simple math facts. They told of feeling inadequate, stupid, and powerless when dealing with school teachers, other psychologists, or advocacy groups. They spoke of years of frustration and despair, especially when Grace became an adolescent and left home to live first with a series of "boyfriends" and then with her abusive husband. They told of their inability to persuade other professionals that their daughter was unable to effectively care for herself, make the simplest of decisions, or raise her children. They had to watch helplessly from the sidelines as their daughter's life fell apart.

They, too, had become voiceless.

In all their contact with social workers, school psychologists, lawyers, and other professionals, no one had told them about Fetal Alcohol Syndrome. Consequently they had laboured alone for many years, knowing that there was something different about their adoptive daughter, but not knowing what, or why. Inevitably, they blamed themselves for Grace's difficulties and ceaseless replayed what they had done, looking for the mistakes which had made Grace the person she had become. By this time, both of Grace's parents were weeping tears of frustration and sorrow.

One day, after approximately one year has gone by, I received a telephone call from Grace. She had followed each of my suggestions and had even moved back to live with her adoptive parents, an option which I had not thought possible. She enrolled in the supported employment training program, successfully completing it and earning her certificate. Unfortunately, however, in one of her work placements she had injured her back and was unable to sit or stand in one position for any length of time, lift heavy objects, or bend without pain. In her struggle to achieve independence, Grace had become even more dependent and she was no longer able to secure the type of employment for which she was suited. She could no longer manage the physical demands of the housekeeping positions she loved and knew she could manage. In her struggle for financial stability and employment, she had once again lost the battle. Now worse off than before, she had no other employment options.

Grace told me that, after moving back to live with her parents, she had sought psychological treatment through support and self-help groups, and had also been prescribed medication for her heightened anxiety. She was reading self-help books, learning about her feelings, exploring who she was and, for the first time, discovering what she wanted from her life. She was also in the process of divorcing her husband and stated that she was no longer interested in marriage, although she might like to date again some day. Grace was voluble and excited with the changes in her life, communicating with an ease which was completely out of character with the woman I had met so many months ago. We made another appointment to meet , since she wanted to see me and tell me how well she was doing.

In the days leading up to this meeting, I wondered about Grace and the things she had told me. It sounded almost too good to be true. She had not only made a concerted effort to follow the suggestions I had made, but had reached past these to try things I would not have believed possible in our initial contact. She had surprised me and made me think about the potential of a future very different from her past. Grace had somehow broken through the barriers erected by her many weaknesses and found the strength to begin again. I could hardly wait to see her but, at the same time I worried that all the positive changes would turn out to be just "talk". I desperately wanted the best for Grace, but still had trouble believing that the best was within her grasp.

Grace and I agreed to meet in a little espresso bar close to my office;

somewhere I would not have expected her to feel comfortable, based on our initial contact. I arrived a bit early and was seated, keeping my eye on the door, completely confident of my ability to pick her out of the crowd waiting for the pre-work jolt of caffeine which signalled the start of another business day. I waited and waited for her to appear, but she did not come. Many other women came and went, but Grace, as I remembered her, was not there. No one matched my internal picture of a frightened little woman; unkempt, ungroomed, and unclean. I became increasingly convinced she had forgotten our meeting or was too intimidated to show up. I was disappointed but not really surprised. It was too much in keeping with all the other times she had not kept appointments.

I gathered my things and turned to leave for the office. As I made my preparations, however, a well-groomed woman with immaculate make-up, a perfect manicure, and stylish clothing approached me and said, "I'm sorry I was a bit late". It was Grace.

I would not have recognized her if she hadn't found me first. Gone was the dishevelled, dirty street person and in her place was someone who looked just like all the other women who had stopped in for their morning coffees. One would have to look long and hard to find the physical evidence of FAS, hidden as it was by the adoption of conventional dress and social behaviours. Yes, Grace was still too small, the deformities in her hands and nails were still unchanged, and her upper lip was still too long and flat but these were not the first things I noticed now. Instead of an FAS-affected

young woman, I saw a young woman. As I greeted her warmly, I realized this spoke much more about my ability to really see Grace than to her acquisition of the trappings of conventionality.

Grace carried herself with a new air of confidence which was so different from her presentation during our initial contact. She could look at people now, unafraid of being judged or dismissed as not good enough. She insisted that she pay for my coffee and, as we drank, she talked about all the changes in her life. She confidently discussed her participation in the self-help groups and thought that she had learned much about herself. She also discussed her need for continued support but now realized she would also be capable of helping others within the group as she had once been helped herself. She talked about her move back home to live with her parents and indicated that she was happy there and, although she wanted to live on her own, she knew she was incapable of supporting herself through competitive employment because of her back injury and the other limitations in intellectual, academic and language functioning. She did not rail against life's unfairness or complain in any way. Rather, she radiated a calmness and serenity that were all the more striking when contrasted with her earlier agitation. Grace was no longer asking for help because she now knew how to help herself.

Grace talked about applying for Assured Income for the Severely Handicapped (AISH), a government program which provides financial support for individuals who are unable to secure or sustain competitive

employment, and I encouraged her in this. I offered her suggestions on the application process, advising her on filling out the appropriate forms with her parents' help and gave her the name of a social worker that I knew. She was greatly excited by the possibility of the limited independence AISH benefits would provide for her and assured me she would make an appointment with the intake social worker that very day.

Grace phoned me some weeks later, almost in tears. Her AISH application had been turned down. Although she had filled out the myriad of forms with the help of her parents and her personal physician, and had attached the report I had first prepared for her, she was rejected because she was deemed not impaired enough to warrant support. Dejected and very afraid of a future with no job prospects or financial stability, Grace was beginning to spiral down again into the fragile, dependent individual she had once been. I reassured her, telling her about the difficulty of being accepted on the basis of an initial application. I explained the appeal process which would give her a second chance and also agreed to write a letter on her behalf.

About two months later, Grace phoned me, ecstatic. She said, "I got it, Val. If you were here, I would hug you." Her appeal had finally been accepted and Grace was now eligible for a supported income, which would be enough for her to live comfortably, if not grandly, for the rest of her life. She told me about all the things she was planning to do. These little extravagances included getting her own apartment and her own phone, and

taking me out for lunch the next time we met. Her confidence and joy, transmitted across the distance, was almost palpable . Grace had finally found her place, perhaps not the one she had expected to find when she first set out from her parent's home so many years ago, but one which was nonetheless comfortable and assured.

Grace and I still keep in touch. She calls me to talk about what has gone on in her life. She invites me for coffee and we hug each other when we meet. We talk about the people we know in common and share the little details of our lives. Our relationship is now one of friendship; unexpected but all the more welcome for this.

Grace is no longer one of the voiceless women. She articulates her feelings and dreams with dignity and a rush of enthusiasm which is contagious. She talks about herself with pride and a sense of her place within her family and her community. Grace has been able to reach inside herself to find the woman who was always there, hidden by the manifestations of FAS. By sheer hard work and with the faithful support of her parents, she has come into her own.

CHAPTER THREE

Theory and Research: The Literature Review

An Overview of Fetal Alcohol Syndrome/Fetal Alcohol Effect

The term "Fetal Alcohol Syndrome" was likely first coined by Jones and Smith (1973) to describe a set of features common in children born to mothers who drank during their pregnancies. In examining the literature of previous centuries, however, various researchers have speculated that early cultures were much more aware of the dangers of maternal alcohol consumption (Light, 1988; Rosman & Oppenheimer, 1985; Streissguth & Martin, 1983). The ancient Greek and Roman philosophers Aristophanes, Euripides, Pliny, and Athenaeus all urged women to abstain or curb their intake of wine. The Bible has several passages which exhort women to refrain from drinking wine. The Talmud also tangentially links paternal drinking with hirsutism and obesity and, although no discussion of maternal drinking is noted, the postbiblical Jewish tradition refrained from giving wine to women (Abel,1984). Abel, however, believes that most of these early prohibitions about the imbibing of alcohol were more related to the supposed uninhibitory effects of wine on a woman's moral character as it was felt to encourage licentious, sexually indecent behaviour. During the course of European history, beginning in the Middle Ages and up to the 17th century, various writers commented on maternal alcohol consumption, again usually

linking it to promiscuity. Early writers did not seem to make any link between adverse effects on the fetus and excessive intake of alcohol and Abel believes that current researchers have erred in trying to establish early precedents for late 20th century discoveries.

During the 18th Century and the Victorian Era in England, however, social commentators were beginning to write about the physical appearance of children born to mothers addicted to gin, which was then cheap, untaxed, and easily obtained. Other writers of the times also commented on the very high rate of stillbirths and the infant mortality rate although these were felt to be more related to socioeconomic class than to alcohol consumption per se. Not until Samuel Howes' (cited in Abel, 1984) 1848 report on "idiocy" did a researcher link parental alcoholism to deleterious effects on offspring. Other British and European researchers (Bezzola, 1901; Sullivan, 1899; Laitenen, 1909) also examined the effects of parental drinking, discovering that periods of heavy drinking usually coincided with a higher than average number of "imbeciles and idiots" being born, increases in infant mortality, stillbirth, spontaneous abortions, and growth delays. The work of these early investigators was opposed, however, by two other researchers (Elderton & Pearson, 1910) who firmly supported the concept of eugenics and who swayed public opinion towards the concept that basic hereditary defects, and not parental alcohol consumption were responsible for intellectual and physical defects. Despite vigorous counter-debate, it was this latter attitude that prevailed and soon was quoted in medical textbooks of the time. Even with animal model studies involving dogs, chickens, guinea pigs, fish, and

mice, which documented problems after parental or fetal exposure to alcohol, researchers of the early 20th Century supported the eugenics argument. Some scientists (Reid, 1903; Stockard, 1913) further stated that alcohol acted as a beneficial agent for mankind as it eliminated weak or defective offspring, thereby leaving only the healthy and strong.

During the 1940's, 1950's, and 1960's, articles in leading medical and scientific journals continued to uphold the eugenics theory of alcohol's effects on fetal and infant development. Not until a French research team (Lemoine, 1969) published a study of 127 children born to alcoholic parents describing a pattern of unique anomalies including growth retardation, peculiar facial features, an increased rate of malformations, and psychomotor disturbances was there any attack on this position. Since this publication was in French and was apparently greeted with considerable skepticism, it had little impact. The work of Jones and Smith (1973) and, later, of Streissguth (1978) was the first to seriously re-establish the significant health risks which follow prenatal exposure to alcohol.

There is an abundance of literature on the clinical aspects of FAS or FAE. Numerous studies have described this syndrome, providing diagnostic criteria and extensive information on young children. Animal studies have provided vital data on the teratogenic nature of alcohol. Isolated studies on the long-term sequelae of FAS or FAE address diagnostic characteristics which change over time (Streissguth, 1994). Exhaustive searches in all existing data bases did not reveal any phenomenological studies of the

effects of maternal alcohol use on children or adults. In addition, no studies which specifically addressed the challenges faced by women with this diagnosis were found.

Definition of FAS and FAE

In diagnosing Fetal Alcohol Syndrome, symptoms must appear in each of three categories: (1) growth deficiency, (2) central nervous system involvement, and (3) characteristic facial dysmorphology. If symptoms are present in fewer than all three diagnostic criteria, then a diagnosis of Fetal Alcohol Effects is usually made, implying that fetal alcohol exposure occurred, but did not result in the full-blown syndrome of characteristics. Some researchers, however, argue that the distinction between FAS and FAE is an artificial one, merely reflecting the differences between the less and more severe ends of a continuum of damage. Others prefer to diagnose "possible Fetal Alcohol Effects" if all three diagnostic criteria are not met.

The Fetal Alcohol Study Group of the Research Society on Alcoholism (Rosett, 1980) formulated a set of diagnostic criteria after a thorough review of FAS and also uphold the concept that characteristics must be present in each of these three categories:

1. Prenatal and/or postnatal growth retardation (weight, length, and head circumference below the 10th percentile when corrected for gestational age;

2. Central nervous system involvement (signs of neurological abnormality, developmental delay, or intellectual impairment)
3. Characteristic facial dysmorphology with at least two of three signs:
   (a) Microcephaly (head circumference below the 3rd percentile)
   (b) Microophthalmia (small eyes) and/or short palpebral fissures
   (c) Flat or absent philtrum, thin upper lip, and/or flattening of the maxillary area.

It must be noted, however, that the possible effects of fetal exposure to alcohol are not limited to just these three areas. Abel (1984) has listed many other characteristics associated with fetal alcohol exposure, including eye problems (i.e., strabismus, nystagmus, myopia, esotropia, and abnormal retinal vasculature), malformations of the head, ears, nose, mouth, palate and jaws, dental anomalies, abnormal development of the heart, liver, and kidneys, urogenital defects, respiratory defects, skin anomalies,and muscular abnormalities. Limb and joint abnormalities, including skeletal anomalies, clubfoot, hip dislocation, fused ribs, spina bifida, and scoliosis have also been identified as common in FAS or FAE.

The diagnostic criteria first established by Rosett (1980) has since been revised and extended under the auspices of the National Academy of Sciences, mandated by the United States Congress (1996). While the original term of Fetal Alcohol Syndrome still stands, it has now been expanded to include other diagnostic markers. Clinicians can now

distinguish between Fetal Alcohol Syndrome with Confirmed Maternal Alcohol Exposure, Fetal Alcohol Syndrome without Confirmed Maternal Alcohol Exposure, and Partial Fetal Alcohol Syndrome with Confirmed Maternal Exposure. The authors suggested replacing the diagnostic category of "Fetal Alcohol Effect" with Alcohol-Related Birth Defects (ARBD) and Alcohol-Related Neurodevelopmental Disorder (ARND). This refinement of diagnostic criteria has attempted to clarify the confusion which clinicians often experienced when making diagnoses without confirmation of maternal alcohol consumption.

Incidence of FAS or FAE

It is difficult to accurately ascertain the rate of FAS or FAE in Canada, partly because of the problems surrounding the diagnostic process. At the time of a report from the Standing Committee on Health and Welfare, Social Affairs, Seniors, and the Status of Women (1992), the incidence rate was estimated at between 1 to two per 1000 live births. At this rate, approximately 400 to 500 Canadian children are born each year with full-blown FAS. This is likely a very conservative estimate, however, as it does not take into consideration the exceptionally high rate of FAS among aboriginal Canadians and other socially disadvantaged groups. In a study of aboriginal groups in the Yukon and northern British Columbia (Asante & Nelms-Matzke, 1985), the incidence rate was 46 per 1000 and 26 per 1000, respectively. In a Vancouver inner city neighbourhood where most families consisted of aboriginal single mothers, a prevalence rate of 50% of live births was not

uncommon (Report of the Standing Committee, 1992).

The incidence rate of FAE births in Canada is currently unknown although some researchers (Casiro, 1992) have stated that FAE is at least three times as frequent as full-blown FAS. If one follows this to its conclusion, then the communities which had a FAS incidence rate of 46 per 1000 births would also have a FAE incidence rate of 138 per 1000. The inner city neighbourhoods with FAS incidence rates of 50% might therefore have virtually no children born without some degree of Fetal Alcohol Effect.

If it is impossible to accurately estimate the number of infants and children born with FAS or FAE, then the task of determining the number of adults already affected is insurmountable. The Standing Committee (1992) stated "based on the estimated incidence rates...there could be tens of thousands of FAS and FAE adults living in Canada today" (p. 28). Many of these individuals have never been correctly diagnosed and few will have received any treatment or care. The lucky few, who are so severely affected that they look different, are likely living in managed care facilities, such as psychiatric hospitals or group homes or other supported living situations. The others, who have the misfortune to only think and act differently, have not been afforded the luxury of assistance. These individuals often eke out a marginal existence, beset by difficulties they are ill-equipped to manage.

Risk Factors

Researchers have established that, while some FAS or FAE damage is due to hypoxia, or lack of oxygen, the toxicity of alcohol itself has not been ruled out. Renwick and Asker (1983) have suggested that the timing of alcohol damage is likely early but the window of sensitivity may extend to the 18th or 20th week of pregnancy. Light (1988) reported that variability in the expression of FAS or FAE also depends on differences in the critical stages of fetal development at which alcohol insult occurs, the impacts of chronic versus binge drinking, and the maximum blood levels attained. He further noted that gross physical malformations were probably produced during the first trimester of pregnancy when the basic development of the central nervous system occurred. Growth was more likely to be affected during the second and third trimesters. Behavioural manifestations of FAS or FAE likely reflected insult in the first trimester, when CNS functional organization is most likely to be affected. Spreen, Risser, and Edgell (1995) also reported that other factors, and not alcohol alone, might account for some of the damage commonly attributed solely to alcohol. Socioeconomic level, poor nutrition, and excessive smoking were all identified as contributors to the pattern of impairment. In addition to these factors, maternal age, weight, number of children born, and genetic susceptibility were seen as playing a part in determining the severity of FAS and FAE.

Adolescents and Adults with FAS or FAE

There are few studies about adolescents and adults with FAS or FAE to be found in the literature. This does not mean, however, that FAS and FAE cease to exist when an affected individual matures, or that the symptoms become less acute. The lack of research in this areas is more likely due to the relatively recent clinical awareness of this syndrome and the resulting lack of longitudinal studies.

Streissguth, Aase, Clarren, Randels, LaDue, and Smith (1991) were one of the first groups of researchers to conduct an extensive follow-up study of adolescents and adults with FAE. They found that the children with FAS reached an average Full Scale IQ of approximately 70, within the mildly Mentally Handicapped/Borderline range of functioning. Adolescents with FAS were in a variety of settings, including regular classroom placements (6%) and self-contained classrooms (28%). Some were in sheltered workshops (9%). Many (15%), however, were not in any formal academic or training settings. Adolescents with FAS were found to have very poor academic skills; reading and spelling were approximately at the Grade 3 to 4 range, respectively. Math skills were even weaker, and at a Grade 2 level.

In addition to the intellectual and academic deficiencies, Streissguth et al documented ongoing poor adaptive behaviour and the 17 year-old subjects of the study functioned like 7 year-olds on a standardized adaptive behaviour scale. Relative strengths in daily living skills contrasted with

significant weaknesses in social functioning and behaviour. Problem areas included very poor cause and effect reasoning, inability to initiate behaviour, unresponsiveness to subtle facial cues, and poor social relationships. These adolescents also had difficulty with poor attention and concentration, dependency, episodes of stubbornness, social withdrawal, teasing or bullying of their peers, emotional lability, insensitivity, unhappiness, and periodic elevated anxiety. Conduct disorders were also prevalent, along with incidents of cheating, lying, stealing, and a disregard for the feelings of others. Attentional disorders, learning disabilities, speech and language problems, and hyperactivity were also noted in this group.

Compounding these problems was a generally unstable family environment. Streissguth et al reported that the majority of FAS-affected individuals had at least five different residential placements in their lifetimes. Only 9% of children with FAS lived with both biological parents. Another 13% lived with their biological mother in single-parent families. By the time FAS-affected children reached adolescence, 69% of biological mothers were known to be dead. Approximately 33% of children with FAS were never raised by their biological mothers and 50% of children with FAS were in foster care (Burd & Martsolf, 1989).

Phelps and Grabowski (1992) also quoted Streissguth and colleagues' (1991) longitudinal study and remarked on the paucity of research on adolescents and adults with FAS and/or FAE. They noted that, while the characteristic facial dysmorphology of FAS was often diminished in

adolescents and adults, the underdeveloped height and head circumference remained. Weight became more normalized, especially for young women although, since these women were often shorter than the norm, they often appeared to be overweight for their height. Intellectual deficits also continued, with functioning within the mildly Mentally Handicapped to Borderline range for those with FAS and FAE. Hyperactivity changed to restlessness and agitation although poor judgment, distractibility, and an inability to perceive common social cues persisted. Phelps and Grabowski also noted the ongoing need for special education assistance for this age range, along with vocational counselling, job training, and instruction in adaptive living skills. The severe behaviour problems often manifested in FAS-affected individuals made typical job training programs unsuitable, however, and continuing intervention and special assistance became necessary.

LaDue (1993) documented the ongoing needs of adolescents and adults with FAS. In adolescents between the ages of 12 and 17, she reported academic weaknesses, increasing social difficulties with isolation as a result, low motivation, egocentricity and an inability to understand or respond to the needs of others, maladaptive behaviours such as lying or stealing, passivity, and faulty logic. Impulsive, aggressive, unpredictable, and violent behaviours, involvement in criminal activities such as vandalism, pregnancy or fathering a child, homelessness, and low self-esteem were also seen as problematic in this age group. Mental health issues such as depression, suicidal ideation and attempts, substance abuse, and sexual/emotional

abuse and trauma were common as well.

Problem areas for adults with FAS included increased expectations and consequent dissatisfaction from significant others; ongoing difficulty with unpredictable, impulsive, and violent behaviours; depression and suicidal ideation or gestures; poor comprehension of conventional social behaviours; social isolation; and a need for economic support and protection. Adults with FAS also experienced social, sexual, and financial exploitation from others; and needed supported medical care, instruction about birth control and sexually transmitted diseases, and help with child care and legal issues.

Streissguth, Barr, Kogan, and Bookstein (1996), in their report on secondary disabilities in individuals with FAS and FAE, reported that individuals in both groups performed relatively poorly on tasks of mental arithmetic, short-term auditory memory, and long-term memory on standardized intelligence tests. For males and females with FAS/FAE more than twelve years of age, males were more likely to have disrupted school experiences, trouble with the law resulting in confinement, and problems with independent living. Females were more likely to have experienced inappropriate sexual behaviour, alcohol/drug problems, and difficulty securing or sustaining employment. Both males and females had similar problems with mental health functioning. Males and females with FAE over the age of 12 were identified as having more difficulties with mental health functioning, disrupted school experiences, criminal behaviours and confinement, inappropriate sexual behaviours, and alcohol/drug problems.

Males and females with FAS over the age of 12 were more likely to have trouble with employment.

In this same study, FAS and FAE-affected individuals from at all ages were most likely to have difficulty with attention deficit disorders. Individuals from ages 21 to 51 were most likely to struggle with depression, suicide threats and attempts, panic attacks, and hallucinatory experiences. Depression and psychotic behaviours first manifested in early adolescence, and treatment for attention deficit problems, depression, inappropriate behaviours was common in individuals with both FAS and FAE. Those with disrupted school experiences were most likely to also have repeated behaviour problems, such as difficulty getting along with peers, disobeying school rules, talking back to teachers, truancy, and fighting. This group were also identified as having repeated attention problems, incomplete school work, grade retention, and specific subject failure. Almost half of the individuals with FAS and FAE were known to have been placed in special education settings, ranging infant stimulation programs through to resource room and special education classrooms.

CHAPTER FOUR

Methodology

In examining the existing literature, I concluded that one of our greatest challenges as a society was determining how to work with those who did not fit into the prescribed framework. While helping professionals had learned that the best way to help another was to ask that person what was needed for success, this practice is not routinely used for individuals who seem unable to help themselves. Despite the knowledge that interventions generated by others were usually not adopted into use or seen as effective by those who were caught up in the problem, helping professionals do not routinely invite the disadvantaged client's ideas about the forms of support he or she think would be genuinely helpful. Instead, decisions are often made for such clients and then, when techniques or strategies fail, blame is laid at the feet of the clients, without questioning the suitability of the intervention measures. A better understanding of the client's situations could be achieved through listening, both to what is said and unsaid, leading to more appropriate helping interventions.

I therefore sought a research orientation which would give me the freedom to both listen and speak. I could not remain separate from the lives of each young woman in this uncovering of their lives. My reactions and my awarenesses were integral to the process of discovery.

Interpretive Inquiry

> Identity means nothing without a set of relations, and...the real work of our time may be defined by an ability to mediate meaning across boundaries and differences, whether those boundaries and differences be concerned with gender, race, or ideas.
>
> (Smith, 1991, p. 203)

Hermeneutics is a set of ideas; a theory about what takes place in the process of interpretation or perception as people construct their knowledge. Knowledge is not objective, waiting to be discovered but is a result of human activity (Smith, 1993). The ideas of philosophical hermeneutics have been best elaborated by Gadamer in Truth and Method (Smith, 1993). Philosophical hermeneutics has informed our awareness of the processes at work in qualitative research. Interpretative inquiry, one form of qualitative research, is distinguished from other forms of qualitative research in that it begins from "concerned engagement"; that is, an expectation of being helpful, rather than from a more distanced intention to increase understanding about some aspect of our world (Packer & Addison, 1989). Packer and Addison (1989) and Ellis (In Press) have written about how interpretative inquiry proceeds in the context of formal research.

In interpretive inquiry, the research begins with a question motivated by practical concern and caring. This question drives the researcher to take some form of action in order to come closer to what she or he hopes to

understand. In coming closer, the researcher discovers both what was expected and what was unexpected. These are the "uncoverings" described. With these uncoverings, research can change direction since new concerns can arise from what was not expected. Questions or concerns can be reframed or refocussed during the data collection process. Uncoverings can also offer new ideas for interpreting and analysing previously collected data. In the initial understanding of the data, the researcher uses his or her own understandings, preconceptions, and prejudices in the forward, projective arc of the hermeneutic circle. In the backward, evaluative arc of the circle the researcher re-examines the data for "confirmation, contradiction, gaps, or inconsistencies" (Ellis, In Press). To evaluate an interpretative account generated from an interpretative inquiry one asks: whether it is plausible, convincing, coherent, and persuasive; whether the researcher's understanding has been transformed; and, whether it offers promising ideas for future activities related to the problem or question.

Packer and Addison (1989) note that fields other than education, including that of psychology, are also becoming aware of a new way of understanding research, which uncovers the connections that tie us to the world and to each other. In the professional literature of psychology, however, "there is comparatively little published writing that addresses the practical and methodological aspects of research conducted from the hermeneutic stance" (p. 3). Writers such as Klein and Westcott (1994) and Osborne (1994) have addressed this need by providing comprehensive discussions of phenomenological research in this field. While philosophical hermeneutics

has clarified what is at work in our interpretation of any entity, phenomenology has heightened our awareness of the uniqueness of each person's experience and perspective. Writings in both philosophical hermeneutics and phenomenology have addressed the project of understanding and expressing another's perspective. These writings highlight the roles of one's fore-structure (prior knowledge) and one's preconceptions (caring and relationship to the problem or question (Ellis, In Press) in beginning to interpret an entity.

Van Manen (1984) describes the first activity of phenomenological research as "turning to a phenomenon which seriously interests us and commits us to the world" (p. 39). Because of this interest, phenomenological research is intrinsically tied to the researcher; it is not seen as separate from the person asking the question, but is rather an extension of that individual's interest and caring. Phenomenological research always begins with an individual whose desire for understanding is tied to her or his personal, social and historical setting. Interpretation is dependent on perspective and, in phenomenological description, no one interpretation is seen as uniquely correct. Van Manen states " a phenomenological description is always *one* interpretation, and no single interpretation of human experience will ever exhaust the possibility of yet another complementary, or even potentially richer, description" (p. 40). Smith (1993, cited in Ellis, In Press) also clarifies that, since understanding is expressed through language, and our language is always changing, there can be no fixed or final interpretation.

Because narrative inquiry is dependent on the researcher's perspective, each researcher brings to her or his interpretations a framework which shapes what is asked. Packer and Addison (1989) state: "Detachment is not an essential prerequisite to objective, undistorted description and explanation. On the contrary, it is a distorting move that removes or covers up the practical involvements - cultural, social and personal - that enable us to understand other people in the first place." (p. 12). Packer and Addison (cited in Ellis, In Press) also point out that it the researcher's caring about the problem and relationship to the problem that enables her or him to "read" or interpret the entity in a particular way. The researcher's connection to and caring about the entity enables her or him to discern meaning and perceive patterns in ways that might not be as apparent to more disinterested "readers of the data".

In interpretive inquiry, methods of exploring the phenomenon can take many forms, but language is an integral part of all. Storytelling or narrative inquiry, personal diaries, interviews, works of art, and conversations are all useful tools to gather "the world...I share with others with whom I communicate" (Smith, 1991, p. 192). Smith further states that language is pivotal in human understanding and contains the story of who we are as a people (p. 190).

Carr (1986) has argued that one can only express one's experiences in narrative form and that each person is compelled to search for coherence in the story of the life she or he is living. While obtaining stories is a promising

approach to learning about another's perspectives, a number of criticisms have been raised regarding narrative accounts. Ellis has summarized some of these, noting that discourse analysts (Florio-Ruane, 1991; Potter & Wetherell, 1987; Wetherell & Potter, 1988, cited in Ellis, In Press) have noted that people may present narrative accounts in different ways on different occasions according to the functions that the accounts are to serve. Ellis also, however, draws attention to aspects of narrative accounts that have an undeniability to them. Narrative accounts support a sense of self or identity through the role of social obligations or commitment. Narrative also maintains the "continuity of...story in terms of...role or relationship" (MacIntyre, cited in Ellis, In Press).

While narrative inquiry can be considered complex even with participants who share language and community with the researcher, my participants of interest were likely to be even more challenging because of their language capabilities and life situations.

Garbarino, Stott, and the faculty of the Erikson Institute (1992) discuss the concept of communicative competence in the interview process and note that "communicative competence requires not only linguistic competence but also an understanding of the social and cultural rules for using language" (p.173). If individuals have limited linguistic proficiency as determined by standard assessment instruments, their ability to adequately express meaning through language might be questioned. As Seidman states, however, "[if] interviewers...have a genuine interest in other people [and are]

deeply aware that other people's stories are of worth in and of themselves, then they will offer something to the interviewer's experience " (p.71). I began my work with the positive expectation that I could learn something important from trying to make sense of the stories each woman would be able to tell me.

Coming to the Questions

Carson (1986) notes " interpreting the prior question which lies behind a problem statement is not totally an analytical process. There is an experience of the world which directs our attention to the question in the first place" (p. 76). In my case, this came from my experiences as a clinical psychologist. Most of my work is in the field of assessment for a variety of learning and intellectual difficulties, including learning disabilities, mental handicap and developmental disability, and emotional/psychological distress. While my practice is not exclusively for women, my referral sources tend to send women to me, especially those whose cases are seen as singularly problematic. This includes women who have been in "the system" for years as well as those who are new to the social services network. In the course of my work, I began to notice a disturbing pattern of dysfunction in a group of women whose backgrounds often shared many commonalities and, primary among them, the consumption of alcohol by their birth mothers.

Although I had a rudimentary knowledge of FAS/FAE, I still had many questions about the lives of the women who sat waiting at my desk. So, like most clinicians trained in quantitative research techniques who have queries,

I began to search the literature and databases for information on FAS or FAE. I was successful in finding information concerning the history of FAS or FAE, animal studies of maternal alcohol consumption at various stages of pregnancy, diagnosis, and childhood educational implications. I was not successful, however, in discovering how an individual who has been diagnosed with FAS or FAE lives because there was nothing in the literature on that topic. I knew about diagnosis and about alcohol's teratogenic nature. I also knew what a FAS or FAE-affected child might look like, but I did not know how a young woman with FAS or FAE lived in the world and how she constructed meaning about her experiences. I did not believe I could make recommendations for effective change without this knowledge and, armed with this desire for understanding and a genuine concern, I put aside my quantitative views to seek a new way of knowing.

I became aware that I wished particularly to focus on the lives of women with FAS or FAE. My need to understand the reality of these women has been difficult to articulate, but perhaps it reflects a calling out to a commonality of experience which shapes all women's lives. I see in their struggles the attempts of every woman to change her situation. Their difficulties have also been my difficulties, and their outcomes might have been mine.

Carson (1986) states "all questioning arises out of the negativity of experience" (p. 75) where all things are not as we hold them to be. This mirrored the contrast between how these women saw their lives and how others saw them. It also reflected the disparity that I observed between these

women's efforts to change and their inability to carry these efforts through to fruition. Their lives seemed especially problematic, not only for the degree of distress they were currently experiencing, but for the ongoing pain and trauma they endured. The depths of these women's distress did not seem to fit the views that others held of them; that they did not care to help themselves, that they preferred to live in a series of dysfunctional relationships, or that they consciously thwarted attempts to effect positive change in their lives. This also did not reflect my understanding as I saw these women as actively engaged in a struggle, albeit a largely unsuccessful one, to alter their circumstances.

Each of the women I met seemed to internalize her inadequacies. She blamed herself for any failings, presenting herself to service agencies only when she could no longer perform even the simplest tasks. Sometimes she did not even know that she could not cope in her various roles as daughter, wife, wage earner, or mother, and so others sought help for her. These women seemed to struggle with a terrible sense of guilt, as if their problems were all of their own making, and they were solely responsible for their despair. I wanted to tell them "I understand. This is not your fault. You did not ask for this reality." I wanted to give their lives a sense of legitimacy and a meaning they did not know they deserved. Each of these women, once we had passed that invisible line which signals trust, wanted to tell her story, "to explain how [she] got to the place [she] currently inhabits" (Steedman, 1987, p. 6).

In working with the parents or caretakers of women affected by maternal alcohol consumption, I was also struck with their desperation. Each in their turn articulated the ongoing disappointments they had faced when dealing with teachers, principals, counsellors, psychologists, psychiatrists, lawyers, police officers, or other professionals who did not understand the particular cluster of behaviours their FAS or FAE daughters manifested. Again, and again, they found that those who were supposed to help them did not know what to do, or did not believe their stories. The caretakers asked for documentation, for corroboration of their children's lives because they had exhausted their ability to articulate their ongoing frustration and fear. They wanted someone else to share the burden, to tell the stories they no longer could, to show that their daughters were not "bad", or crazy, or poorly parented. They wanted someone to give them a framework for their desperation.

Most of these parents felt powerless and out of control. They had been unable to present their needs and the needs of their children. Many of them had made the rounds of professionals for many years, knowing at some level that their child did not learn or behave the way other children did. Although they knew they were likely not alone in their struggles, they were unable to effectively ask for assistance. They too, had become voiceless.

The participants in this research were not used to being considered as important sources of information. They were like the silent women described by Belenky, Clinchy, Goldberger, and Tarule, in Women's Ways of Knowing

(1986). These women were used to hearing voices raised in anger and frustration, but not in joy. They knew that words have power, but did not believe they had any right to wield this for their own sakes. Words represented the control of outsiders who do not understand the realities of lives lived out in silence, where language is just another trick used by those who have to manipulate those who have not.

The silent women were not only isolated from others, they were isolated from their own capacity to make meaning from their experiences. Because no one had listened to them, they did not know how to listen to themselves. They had no confidence in their own words. They did not see the relationship between language and the ability to learn from what happens each day. Without this interchange, these women remained isolated from each other, from the larger community, and from themselves.

In my discussion with Grace, she revealed that words were things that got her into trouble. If she spoke out of turn, her husband beat her. When she tried to stand up for herself after he left her for another woman, she was charged with making harassing telephone calls. When she spoke honestly to the police about the circumstances surrounding the charges of child sexual abuse, she was convicted. Words did not help Grace to formulate any understanding. Instead, they only waited to trip her up; to show her just where she was wrong and how she didn't fit in. For her, and women like her, words were the enemy.

Grace was one of the silent women who had learned that words are for others and not for them. She did not understand that words can bring a sense of control and equality in one's relationships with others. She did not know that she had a voice and so she did not learn to listen to herself. Because she had not learned to listen to herself, she could not listen to others. Grace described herself as a "doer", not a "talker". This poignant comment sums up all the silent women, who do not believe in their own capabilities.

In this research, it was hoped that each of the five women would hear her own voice and believe in its strength. These women were accustomed to being told what to do by others. It was hoped that they could also develop their own understanding by reflecting on their own experiences and making sense of their lives.

Interview Questions

The guiding questions I used to explore each woman's understanding of her day-to-day life experiences were derived from the work of Belenky, Clinchy, Goldberger, and Tarule (1986) (Appendix B). These questions provided an opportunity for each woman to address the recollections of her life and the issues which assumed prominence for her. These, in turn, shed light on the memories which guided her self-image and her current way of being in the world. The recollections also provided information about how each participant was aware of the potential for change in her life and how to

best access that potential.

With regards to establishing positive intervention strategies for women with FAS or FAE, the questions focused on the assistance each woman felt she needed at various stages in her life, in order to deal with the areas of concern which were articulated in the earlier questions. The participants were also questioned about who they felt could have best provided this assistance. In addition, each woman was asked what interventions she believed would have been helpful to other women in similar circumstances.

Participants

The five women participants were selected from a larger group of women, approximately two hundred each year, who had been referred to my clinical practice by government agencies for help, either with lifestyle issues or with vocational difficulties, or a combination of both. Some of these women, about four percent of my client population, were affected by FAS or FAE. In practical terms, this meant that of the four to five women I saw each week, at least one had been affected by alcohol in utero.

Each of the participants in this research was representative of many of the women I had seen but somehow different from them as well. Many of my clients were poor, as they were. Many were young, single parents, as many of this group were, too. Most could not articulate a consistent support network or recall personal histories full of successes or triumphs, also like these five

women. They seemed similar in many ways, but they were not. Despite the commonalities, there was something intangibly different about their circumstances which drew my attention back, and then back again. Although the commonalities far outweighed the differences, the differences were there. Among all the sad and desperate stories I heard over and over in my practice, each of these women's histories had a poignancy which transcended the commonplace tragedies of personal and vocational failure to which I bore witness.

These young women seemed to have more than their share of insurmountable problems. They could not understand their own limitations. Unlike my other clients, who usually understood their weaknesses all too well, these women repeated the same errors of judgement over and over again, without realising that these were errors. They did not understand how to make changes in their lives because they did not know they needed to change. They had little self-awareness and could not articulate their feelings; they did not know they were capable of more than rage or despair. Happiness and contentment were unfamiliar emotions which often made them wary. They were too transient to be trusted.

These five women were representative of the many women with FAS or FAE that I had worked with over the past six years in my practice, but they had one major difference. I knew how to find them. They had not slipped back into the shadows of the city, where they became invisible to me and to the government agencies which had been set up to work with disadvantaged

populations. Each of these women was still somehow within the system of social services; they had not become disillusioned enough to try their luck in another part of Alberta or in another province. There were many other women whose stories were equally poignant but I had lost them. I no longer knew where they were.

Because of the transience of this group, I did not have the luxury of an unlimited number of clients from which to choose. I had previously spent several fruitless months trying to locate women with whom I had worked and had met with little success. Most of the women were simply gone. They had been dropped from their social worker's caseload because they been noncompliant or unable to carry out their worker's recommendations, or they were just not there. Some of them might have been in jail. Some of them might have died. None of them lived at the old addresses I had. None of them had the same telephone numbers. I could not find them. They had become invisible and I therefore chose to work with the women I could reach; the ones who had not yet given up hope and moved on.

I also chose to work with women between the ages of 18 and 25 years. Most of the women with whom I worked fell within these age parameters but I found that these years were especially problematic for young women with FAS or FAE. It is a time when many other individuals of that chronological age are developing a sense of self, independent from their families. They are, for the most part, living on their own, paying their own bills; going to school, or working to support themselves or a family. They have become

accepted members of a social system; a part of the greater community. Many of the young women I saw did not share that sense of inclusion. Most had acquired the trappings of independence, but not the skills which support self-sufficiency. While most lived apart from their families, they were still tied to them by their own inability to cope with decision-making or financial responsibility. Many had young children, but not the skills to parent them effectively. Many were involved in relationships, but did not understand how to communicate or manage the day-to-day stresses which affect every partnership. These young women were not the same as their age peers, no matter how many outward signs of "sameness" they adopted. The details escaped them; they could see the "gestalt" but not all the little details which go into making a cohesive whole.

These young women understood the pressure to live independently but could not manage the day-to-day details of handling utility bills, negotiating a damage deposit on a rental accommodation, signing a lease, or being a good tenant. They could not understand how to cope with the myriad demands which independent living requires. They only understood what one needs to do to look like everyone else; live on your own, have a baby, go to school, find a man.

Each woman was referred to my office because some aspect or aspects of her life had been identified as problematic. There were questions about her functioning that the other agencies or institutions involved in her care had been unable to answer. There were gaps in the knowledge needed to

provide appropriate assistance. Often, there were no attempts made by other professionals to establish the patterns of dysfunctional behaviour, because of the sense of urgency which always surrounded women like these. Prior to my involvement, medical, educational, and personal histories had not been gathered. There was little integration between a woman's past and her present. The important minutiae were not gathered and, because these women did not see the importance of detail, it was not offered. I became a detective; tracking down the small importances which established the pattern of each woman's life.

Each woman had had a comprehensive psychological assessment by this researcher to establish cognitive, academic, receptive/expressive language functioning, adaptive behaviour, and emotional functioning. An in-depth clinical interview was part of the diagnostic process (Appendix A) and a diagnosis of FAS or FAE was made. The diagnostic process was a integral component of this research. The women who had been sent to me were expecting me to do something. To sit and talk, to them, was to do nothing. They had had that before and discussion had not led to tangible change in their lives. Words, especially the words of others, were meaningless; so much static that only confused them and made them feel stupid because they could not talk as glibly. For these women, dialogue was a time-filler; what you did when you were waiting for action. If you could do something, you did it. If you couldn't, you talked to fill up the emptiness where action was supposed to be.

In their world, people of consequence made things happen. They did not sit around and talk. So, we did things. We went through a comprehensive psychological battery. We examined motor functioning, intellectual skills, linguistic competence, academic capabilities, adaptive behaviour, and emotional functioning. We did things together and they did things on their own, but they did "something". They had a sense they were active participants in the process. They had become part of the solution, rather than part of the problem.

The act of participating in a dialogue was a new and interesting experience for each woman. These were women who were usually lost and confused in the give-and-take of everyday conversation. They could not keep track of the rapid flow of ideas which typifies conversation among equals. Discussion made them angry or fearful. They stood on the outskirts, listening desperately, hoping for an opening into which they could thrust their voices. They were the silent watchers on the edge, waiting for others to laugh so they could join in.

Part of the diagnostic process was a comprehensive, semi-structured clinical interview. This question-and-answer experience gave each participant a framework for her words, a comforting structure around which she could wrap her dialogue. She was not forced to confront her own linguistic deficiencies but instead developed a sense of the meaningfulness of her own language in an atmosphere of acceptance and support. She was asked factual questions, ones that she could answer, and then as the

interview progressed, the questions became more open-ended, less factual, and more personal. The flow had been guided from the known to the unknown, and she could keep pace. Each woman's words had become important; valuable enough to warrant another's undivided attention and time. Each was listened to, with no interruptions to make her doubt what she had said. Her words were written down, with her permission; concrete evidence of communication between two people.

These women acquired a sense of who they were by doing things. They wanted to know what they could realistically accomplish. They did not buy the line that one only has to try hard enough to succeed in anything. This had never worked for them before and wasn't going to work this time. I respected them too much to give them this lie once again. There was always a great sense of relief when I told them that they were right, that they had known themselves better than anyone, and that there were things they really couldn't do. This had nothing to do with their ability to try, with laziness, or with a "bad attitude". It had everything to do with their capabilities. And, in being released from the inappropriate expectations of others, they had been freed to be who they really were.

These women knew that there was something wrong in their ability to cope with the demands of the larger world. Too often, they had interpreted this meant that there was something wrong with them. I wanted to change their focus, to reframe their understanding to help them see that what was "wrong" were the expectations and demands placed on them. Only by

examining their skills could we begin the process of rebuilding competence and a sense of self.

In the second interview, conducted after the clinical assessment, each woman was interviewed using a open-ended, flexible interview format (Appendix B). This interview provided each participant with a forum to recollect her memories of her family of origin, schooling, personal understanding, gender, relationships, ways of handling dilemmas, and possibilities for intervention. Although it was the researcher's intention to tape record each interview, this decision was negotiated with each participant. Some women were hesitant to have their stories recorded and their wishes were respected. The researcher also took notes during the interview as this was something with which they were comfortable and familiar. I followed University of Alberta guidelines with respect to the rights of, and risks to, participants' confidentiality and researcher competence.

It was often difficult to find these women to conduct the second interview, after my initial involvement was over. They were highly transient; moving from one rooming house, apartment, or rental accommodation to another. They left town for a week or two, or a month; sometimes returning and sometimes not. The only constants in their lives were often their social workers, who themselves were becoming increasingly hard to find as a result of governmental downsizing and departmental fragmentation. I was occasionally forced to use my contacts within various government departments, asking if a sympathetic worker could track down one of these

women through a Social Insurance number or transferred file. Sometimes I was lucky. Sometimes I was not and so I learned to wait.

Although I tried to maintain telephone contact, this was very hard to do. These women's highly transient lifestyles and tendency to forget to pay bills often meant that they often did not have telephones. I used their network of friends and family members to leave messages. I used their social workers or career counsellors. Sometimes there was no one to use. And I waited.

While each of these women would occasionally drift into my office, this was usually a reflection of their needs, not mine. I learned to respect their sense of when further contact was desirable rather than imposing my timeframe on them. Pressure was not something they managed well. The expectations of others, even of those they liked, made them uncomfortable. I learned to be patient, to wait until they wanted to see me. Sometimes they did not want to see me for weeks, or even months. And sometimes, they did not want to see me at all.

Although this waiting period was very frustrating, it was productive. I had the time I needed to think about their impact on me and about my impact on them. They gave me a gift of time and I used that gift to listen to what they had told me. I had a reflective space to step back from the immediate tragedies of their lives and find the small celebrations that I might have otherwise missed. I could wait to see if my intervention had resulted in any positive change.

In my capacity as a clinical psychologist, I usually have only a short time to meet someone, assess his or her needs, and develop intervention strategies. Once I make my recommendations, my contact is often over. I am rarely privy to what happens after my involvement. I am unable to rejoice in the positives or mourn the losses. I am simultaneously involved and uninvolved; a precarious balancing act. I often think about the people I see, wondering if I was able to help or if I met their needs. I may believe I made the best suggestions, but I rarely have my perceptions verified. I find things out second or third-hand, or not at all. I am always left with questions, and I do not appreciate this. I like to know.

With these five women, however, I had the privilege of seeing the effects of my intervention. They allowed me to be involved. With them, I did not need to balance. I was involved with all of the attendant stresses and "shoulds" that participation demands. I was one of "us", not one of "them". Although I had entered their lives uninvited, they graciously asked me to stay.

Conducting the Interviews

A structured, clinical interview was part of the initial assessment, to ensure that participants were appropriate for this study. After this, however, a flexible, open-ended individual interview, which took place at a later date, was chosen for the second component of this research. This provided a less formal, more conversational setting for each personal history. Although a structured interview was necessary for the clinical assessment, it would have

been too rigid a format for the in-depth interview, inhibiting natural conversation in a group who generally have significantly weak receptive and expressive language functioning. To ensure that each participant felt comfortable with the process, no attempts to censor the participants' verbal expression were made in the interview, despite the often uninhibited vocabulary noted in individuals with poor social functioning . As Bogdan and Biklen (1992) noted, "when the interviewer controls the content too rigidly, when the subject cannot tell his or her story personally in his or her own words, the interview falls out of the qualitative range" (p. 97).

The length of time for each open-ended interview was controlled by the client, and each meeting was conducted in a familiar, convenient office location to which the woman had previously been. This further encouraged a degree of comfort with the interview process, as many of these women were wary in unfamiliar settings and with individuals whom they did not know. As previously mentioned, each interview was tape-recorded and then transcribed, if the participant agreed.

The stimulus topics in the semi-structured interview were intended to provide an open-ended format in which the participant was free to discuss her personal history as she wished. Each topic, which was designed as a trigger point to stimulate a more free-flowing conversational style and to ensure that all important points were addressed, was introduced in as simple language as possible. Each topic was generated from the researcher's own understanding of FAS or FAE, from the literature on FAS or FAE across the

lifespan and from literature on phenomenological research with women, and from the researcher's prior knowledge of each participant's life experiences.

The researcher also used the interview format found in Belenky, Clinchy, Goldberger, and Tarule's Women's Ways of Knowing (1986). This format was used with women of divergent ages, and social and educational backgrounds to explore how women see their realities and "draw conclusions about truth, knowledge, and authority" (p. 3). These researchers used an interview approach to ensure that they would be able to hear what each woman had to say in her own language, since their study included "a number of disadvantaged and forgotten women whose ways of knowing and learning, [and] identity transformations" (p. 11) had rarely been examined in academic research.

Interpreting the Interviews

Working from notes and/or transcripts, analysis focussed on identifying common experiences and themes among participants. It was hoped that each participant would tell about her experiences in her family of origin and in the larger community. Issues of personal growth, change, and transition were explored, in addition to each woman's concept of self and awareness of personal growth. Each woman was also asked to share her thoughts about potential intervention techniques which might have benefitted her or which might help other women in similar situations. Themes continued to emerge as the study progressed; some these named by the participants themselves

and some framed by the researcher's interpretation of what had been revealed through the process of inquiry.

In interpretative inquiry, the writing can take many forms. As van Manen (1984) noted, "there is no compelling reason for structuring a phenomenological description in any one particular way" (p. 66) aside from making it consistent with the essential nature of the phenomenon one is exploring. He provided several alternative ways to organize descriptions, but note that each of these methods can be used, either singly or in combination, to go back and forth between "these various levels of questioning" (p. 68). Each had its own particular structure and power, although none were "neither exhaustive or mutually exclusive" (p. 67).

In working with these women, their stories wove the different ways of structuring descriptions into a surprising complexity. Themes which I had not expected arose from the narratives which had, at first, seemed so simple and direct. These themes organized themselves into a pattern which led to an "ever deepening search for ground (van Manen, p. 66) and drove me onward to discover how these women lived within the wider community. I also looked for the works of other researchers in the field of FAS and FAE, to examine their understanding of the issues faced by other adults who shared this diagnosis.

Boundaries

The individuals in this research had been agency-referred for ongoing

difficulty with vocational functioning or chronic lifestyle problems. Because of the caring and concern which drove this study, this researcher also elected to work with young women who had significant problem areas in their lives. There may be, however, other young women with this syndrome who cope more appropriately with their difficulties and who are able to make appropriate personal choices. There may also be other young women with FAS or FAE who have a stronger support network. Most of the participants in this study had been living on their own for many years and had few of the traditional sources of support, such as friends, partners, or family members. Again, there might have been other young women who were not as isolated and who could access assistance, if it was required.

Importance of the Study

There are several areas of significance in this study. The major significance of lies in providing important information regarding the lives of young urban women affected with FAS or FAE. Knowledge of their concept of self, living conditions, mental health functioning, problem solving skills, and coping mechanisms is unclear. Helping professionals who effect intervention strategies are doing so with little understanding of the day-to-day issues with which these women cope.

An equally significant aspect of this study is in the possibility of greater understanding of gender as it affects one's experiences living with FAS or FAE. No research has thus far focussed on FAS or FAE women's lives,

leaving a significant gap in the professional understanding of this syndrome.

A third significant aspect of this study is in the potential for greater understanding of the long-term effects of a disorder which so far has focussed primarily on infants and young children. The information available on older populations is extremely sparse and provides information on physiology, rather than issues of social/emotional functioning, personal awareness, and problem solving strategies.

The research process itself is also thought to be significant as it encouraged a parity in relationships with women who are accustomed to little power. The act of collaboration engendered feelings of increased self-worth and a sense of place in the community.

An additional source of significance is in each woman's recollections of her school experiences. Her understanding of the value of formal education had the potential to provide teachers with information to ensure that FAS or FAE-affected girls and women were provided with appropriate, positive educational experiences.

CHAPTER FIVE

Sherry's Story

Sherry was referred to me by her social worker. She had recently given birth and there were serious questions about her ability to parent her young son, aged six months. She and her child were living in a therapeutic foster home where the foster mother had responsibility for parenting both Sherry and her infant. Sherry did not like this situation and was waiting, not very patiently, for Social Services to give her full custody of her child. She alternated between thinking there were no problems with her parenting skills, lifestyle, or ability to function independently and wanting to give up her baby because she was unable to handle his simple demands for warmth, food, and nuturing.

Sherry had considerable difficulty living with the restrictions of her therapeutic foster home and frequently left it, for a few days or a week at a time. She did not like being told when to brush her teeth or change her clothing. She thought she was capable of making these simple decisions in her own. In our ongoing contact, however, it was very clear that she could not make these choices independently. There were some appointments, after she had been on her own for a week or two, when I could not bear to sit across the desk from her because her breath and body odour were so foul. On these occasions, her clothes were wrinkled, dirty, and worn in many layers; she clearly had not washed her clothing or her person in all the days

she had been absent from the foster home.

When Sherry was on her own, she lived with a series of "friends" and boyfriends, returning to her therapeutic placement when she had been thrown out of wherever she was staying. There was a strong suggestion of continued prostitution but no one involved in her case had any conclusive proof that she was resuming her previous lifestyle. On these AWOL periods, Sherry often dropped into my office to tell me where she was, or what others were trying to do to her, or to complain that Social Services were not letting her have her baby back. She often wept, asking for help to get custody of her child. She tried to pretend she and the baby's father were not in an ongoing relationship but she would forget and tell me what she and Darryl had done that morning, or the night before. Sherry was a very poor liar.

Sherry's social worker flippantly called her "...the poster child for Fetal Alcohol Syndrome...", and she was right. Sherry was tiny and fragile, and at the age of 23, was shorter and weighed less than the average eleven year old. She had the small head; wide-set, tiny eyes; underdeveloped mid-face; long, flat upper lip; deformed and misplaced ears; and missing philtrum characteristic of FAS. Her teeth were crowded into her lower jaw, and when she spoke, it was with a noticeable articulation defect. Her hands were small and the baby finger on each hand was too tiny, crooked and so harshly bent outwards at the first joint it formed an angle rather than a gentle inward curve.

Sherry told me about her early history with surprisingly articulate recall.

She was apprehended from her birth mother at five months, and adopted from a foster home at age four. Her adoptive family were American and she was taken to the United States. When her new family subsequently adopted another infant, she became jealous and would often hit the new baby. She was harshly disciplined for her misbehaviour, locked in the basement or outside, or beaten with a wooden spoon. She was removed from this home and placed in another American foster home where her beatings were even more frequent and severe.

In addition to the physical abuse in this foster home, Sherry was raped at age 9 by a 16-year old foster brother and then subjected to ongoing sexual abuse until she was removed from this home at age 11. She was then moved to another American foster placement where there was less physical abuse and no sexual abuse. She remained there for a year and a half, and was then placed in what she called a "mental hospital". Although no one hit her there, she did not like this place because there were too many rules that she did not understand and could not follow. Sherry had two other foster placements where she was subjected to additional physical and sexual abuse. At age 14, she was returned to Canada. She did not know why this had happened. She was merely in America one day, and then in Canada the next.

Back in Winnipeg, her birth city, Sherry was placed in a series of treatment centres and foster homes. Most of these were not positive experiences and, in one, she was diagnosed with schizophrenia, perhaps

because of flashbacks from the repeated incidents of sexual abuse. After an adult therapeutic placement broke down, Sherry decided to live on her own at the age of 19. She earned money the only way she knew how, supporting herself and a series of common-law partners through prostitution. She used drugs and drank during this time, and often scrounged through dumpsters for food. Sherry was also periodically on Social Assistance, usually when a relationship had ended and there was no one to look after her. Her many relationships were stormy and characterised by physical abuse. She often resorted to women's shelters to escape from the beatings but usually returned to the streets because she had nowhere else to go. During her years on the street, Sherry had three pregnancies which all ended in miscarriages. At the age of 23, she had been pregnant five times, and given birth once.

Sherry left Winnipeg to come to Edmonton because another physically abusive partner had outstanding warrants in Alberta and she knew he would not follow her here. When she first arrived in Edmonton, she lived for a time in a women's shelter in Sherwood Park and then moved to a women's hostel. She next moved in with another man but he was also abusive and so she left him.

Sherry was in the process of divorcing the first man she had ever married, the father of her child. She met Darryl when she was on her way to an inner city co-operative centre as he was coming out of a pawn shop. She became pregnant at her husband's urging as she said that he did not feel like a man if she was not pregnant, and she felt very guilty about her inability to

provide him with a child. Her first pregnancy with him ended in miscarriage in the first trimester. Her second pregnancy resulted in the birth of her son, five weeks premature.

Sherry's marriage was extremely troubled and characterised by violence, abuse, and alcohol and drug use. She and her husband frequently fought and their arguments easily escalated into physical assaults. These were especially vicious whenever Sherry was pregnant, and she blamed her unborn child for making her so angry. She thought that her rage was a result of the fetus' hunger and felt her bouts of screaming, hitting, and throwing things were justifiable, because "the baby was hungry". Sherry also thought that other people were responsible for her anger because their expectations were too high.

Sherry's relationship with her husband was also punctuated by her prostitution as a means of supporting their drug habits, and frequent, short-lived separations. When I was first involved with Sherry, she was in the process of divorcing her husband, but then left the therapeutic home to live with him for periods of a week at a time. At my last contact, she and Darryl were back together again, and the divorce was off. Sherry thought that the only thing keeping her from a stable relationship with Darryl was the absence of her young son. She was certain that her marriage would work, if only her son was returned to her.

Sherry remembered that school had been difficult for her and she was

always in special education settings. Although she believed she could read, perform math calculations and spell adequately, she knew she could not understand much of what she read. Sherry's favourite occupation was watching "The Young and the Restless", a long-running soap opera, and we shared an animated conversation about what Nikki and Danny, and Brad and Victor were up to lately. Sherry told me she just couldn't look after her young son when "The Young and the Restless" was on. The foster mother was forced care for her son during that hour because she was so caught up in the events on television, she could not hear him crying .

Sherry held several entry-level unskilled positions in Winnipeg, including clearing tables at fast food restaurants, dishwashing, and cleaning parking lots. She liked to wash dishes and was willing to do this again. Sherry had few pre-employment skills and did not know how to dress or conduct herself in a manner designed to impress a potential employer. Even if she did know how to dress for a job interview, she had no suitable clothes. Apart from episodic prostitution, she had never been employed in Edmonton although she occasionally relied on income from unreported babysitting to support herself. She apparently had little difficulty finding clients who wanted her to care for their children, in spite of Social Service's concerns about her ability to care for her own child, even in a therapeutic foster setting.

Sherry knew that she had been born prematurely, at 32 weeks gestation. She volunteered, "Momma drank when she was pregnant with me". At birth, she had respiratory and cardiac problems. From what she

reported, she also might have had Failure to Thrive, but this is a term she did not know and so she did not recognize it when I asked about it. Sherry had scoliosis and had suffered chronic upper respiratory tract infections and ear infections for years. Sherry still had problems with her hearing, especially in her left ear, and had tinnitis in both ears. She was prescribed glasses but didn't have any. She thought her vision was "fine".

Sherry's cognitive and language skills were extremely weak although her spelling was surprisingly well developed. The rest of her academic skills were well below the level required for functional literacy and Sherry could not read well enough to mix baby formula, follow a simple recipe, or find a phone number. She could not read a map or street signs and navigated in the familiar territory of Edmonton's downtown "Drag", the area where the street prostitutes hang out, by landmarks, not addresses.

In my last contact with Sherry, we met in my office, along with the social worker managing her case. Darryl was not there, although Sherry stated that their marriage was back on again. I told her of my concerns for her child and for her. I also told her that I thought she did not have the skills to look after her son consistently and caringly, despite all of her protestations. I told her that I did not think she was ready to look after her child and that being a parent meant more than merely wanting a baby to make one's partner "feel like a man".

Sherry was very angry with me and shouted that I was ruining her life. I

knew, however, that that particular blame could not be laid at my feet. The shambles of her life were shadowed by the legacy of a woman who, 23 years ago, couldn't stop drinking when she was pregnant. Sherry was a victim of someone else's problems; the evidence of another person's slow slide toward self-destruction.

Sherry did not get custody of her child but the court date was still pending. With good counsel, it was possible that she could be awarded full custody of her young son, and I had learned never to predict the outcome of any case. Once again, whatever the final decision, I would be called to provide "expert witness" testimony to establish that Sherry was impaired and incapable of fulfilling one of society's most basic, but most important roles. I would have to articulate her inability to parent and perhaps take away one of the few ways she could be like other women. I did accept responsibility for that.

Janice's Story

Janice was referred to me by a government agency because she called her social worker and admitted she was unable to care for her two young children. She was pregnant, likely with twins, and this pregnancy was not going well. She felt sick, lethargic, and depressed. The father of the twins had recently abandoned the family because he was struggling with custody issues concerning another daughter in British Columbia. When he left, he told Janice to terminate the pregnancy and, all alone, Janice was unable to

decide what to do. Janice's two daughters had speech/language delays and the youngest child was in an early intervention program. A parent aide was placed in the home because Janice became physically abusive towards her youngest child, hitting her with a plastic spoon and leaving bruises.

Janice alternated between wanting to give up her children and worrying about being alone. When others asked her about the children, she often lied, saying she was babysitting, or that her two little girls were her sisters or her nieces. She had few feelings of responsibility towards her oldest daughter, and stated she had only kept this child at her mother's urging. She had really wanted to give this baby up for adoption. She referred to her oldest child as her mother's daughter. Janice was closer to her youngest child, the one she beat. She hit her because she loved her; she wanted to teach her right from wrong. Janice did not care if her oldest daughter learned the same lessons. This was not her child and therefore not her responsibility. Janice reported that both girls had different fathers; these men had not provided financial support for their children. The father of her most recent pregnancy would also not be around to support these children; he had left her to care for another child by another woman in another province.

Although Janice was in the second trimester of her pregnancy, she did not look pregnant. Instead, she appeared fragile and exhausted. She, too, was tiny, with a head too small and narrow, and a misshapen, flattened nose. She took off her shoes to show me her feet, which were very flat and wide.

The fourth toe on each foot was extremely small, misshapen, and very out of line with her other toes. She proudly told me that these toes had no bones in them.

Janice's speech was unclear and she had an articulation defect which sometimes made her difficult to understand. She often searched for the words to express herself and her conversation was halting and disjointed. She often mispronounced common words and expressions. She could not say "of course". It sounded more like "a course". She sounded uneducated, and so she was. She had made it all the way to high school, reading at less than a Grade 3 level. Her writing and math calculations skills were slightly stronger but still below Grade 5. It was not surprising that she could not manage the demands of regular Grade 10 coursework in her last attempt to return to school. She had told the school officials and her social worker this, but they had not listened to her. She was unable to ask for what she needed. She was voiceless.

Janice announced with a smile that her health was "perfect" in spite of ongoing treatment for sexually transmitted diseases. She was unsure about the results of testing for the herpes virus and thought she might also have vaginal warts. Janice had unprotected sexual intercourse with an actively ill, HIV-positive man on at least two occasions, even after she knew he was ill, but so far had apparently tested negative for the virus which causes AIDS. She was also being treated for precancerous cervical cells although this condition had not responded well to laser surgery and ongoing treatment

would be required. Janice wanted to have a tubal ligation as she was tired of being pregnant. At the age of 20, she had been pregnant five times.

Janice's history was complicated by a premature birth, respiratory distress, and gestational immaturity. She did not breathe on her own at birth and was placed in a Neonatal Intensive Care unit. As an infant and young child, she had repeated hospital admissions for pneumonia, conjunctivitis, severe sinus infections, and croup. As a child, her weight, height, and head circumference were all below age expectations. She had asthma and used an inhaler whenever she was excited or nervous. Her asthma had not stopped her from smoking marijuana although she was quite proud that she did not smoke cigarettes. Janice was hit by a car at the age of seven or eight but she could not remember her exact age when this happened. Although she apparently hit her head, she was never examined by a doctor or taken to a hospital.

Janice attended many schools in Alberta and Ontario. She was unable to remember the names of any of the local elementary schools, apart from one. She failed Grades 1 and 3, and also had special class placements but these interventions did not help her weak reading and spelling skills. She did not have friends in school and preferred to be by herself. Janice eventually left school in Grade 9 when she became pregnant. Although she was offered a spot in an alternative school program for pregnant teens, she did not attend because she thought she was "too pregnant". Janice tried to return to school to complete her high school courses on two separate occasions but was

unsuccessful each time. She had numerous psychoeducational assessments but was never given any results, even at the last assessment, approximately two years before her referral to me.

Janice had limited work experience through a vocational junior high school program and really enjoyed her placement at a frame shop. She worked for a short time as a waitress and also was employed at a carwash and as a retail sales clerk, but was fired from both positions. She did not know why. Janice had some experience as a casual babysitter as well, despite her problems in caring for her own children. She could not articulate any vocational goals and was not sure if she should return to school for academic upgrading.

Janice could not remember much of her childhood but did recall ongoing sexual abuse, from ages 8 to 12, at the hands of an older man, a friend of the family. This individual also sexually abused her mother and her aunt, but her mother still left Janice in his care. He was charged and convicted of abusing Janice and her younger sister but died before he served his sentence. She was very angry about this and about her mother's failure to adequately care for her.

Janice was afraid of her temper. She could only cope with her emotions by withdrawing and physically isolating herself, and her children were often left alone while she raged in her bedroom or the bathroom, with the door locked. She tried to kill herself twice with drug overdoses, once

using Tylenol and once using birth control pills. She took the birth control pills because they were the only ones available to her. As a result, she was left without contraceptives for a month and subsequently became pregnant.

Janice's relationship with her mother was very troubled and they often fought. Janice worried that she could never do things well enough to please her mother although she still tried to make her mother proud. In spite of their inability to get along, Janice indicated that she had no other supports and was very frightened about being alone. Her mother often cared for Janice's young daughters, even though Janice felt she yelled at the children too much. Janice's mother had often hit her with spoons, belts, or her hands when Janice was younger but she did not think that her mother abused her grandchildren in the same way.

Janice had a younger sister, but said she did not see her very often, and their relationship was also troubled. Janice said her sister was a prostitute, who had a lengthy criminal record for soliciting, break and enter, and assault. Despite their difficulties, Janice recently spent a weekend with her sister, drinking and using drugs. She did not think that this would have much impact on her pregnancy and thought that it was her right to drink, dance and have fun. Janice also could recall other incidents where she was very drunk, even after she knew she was pregnant. She did not think this was "hurting anyone".

Janice was alone, after her boyfriend left her. She was very frightened

by this and could not understand why this relationship had soured. She said she had done everything for this man, cutting his hair, bathing him, and looking after his every need. She described herself as very bitter towards him and, although no one had been allowed to sit in his chair since he left, she took scissors and cut up everything he left in the apartment.

Candy's Story

I was asked to see Candy by her social worker and youth worker, who were extremely worried about some of her high-risk behaviours. Candy had spent considerable time in secure treatment, both in Edmonton and Calgary, because she had repeatedly been unable to cope with less restrictive living situations in therapeutic group homes or foster placements. Candy had not lived at home for several years and her infrequent contact with her family was strained and usually hostile. In her current residential setting in a therapeutic group home, she often ran away, usually on the weekends, and there was strong suspicion that she was prostituting herself on the streets. Her youth worker also expressed fear that Candy was using drugs and drinking heavily, and there seemed to be few options for treating her defiant, unsafe behaviours. At the time of our first contact, she was 17.

Although Candy was enrolled in a special education program at a local high school, she was often absent, and one of her teachers reported a pattern of escalating agitation which usually resulted in an extended "weekend" that began on Thursday or Friday, and ended on Monday mornings. She usually

attended classes only Monday through Wednesday. Candy herself thought that school was a waste of time, now that she was a teenager. She had other things to learn and other things to do with her life.

Candy's youth worker, whom I had met before, warned me that this case would tug at my heart. I didn't know how true this would be. I thought I was hardened to the circumstances of my clients and I dismissed her warning. I shouldn't have; she knew what she was talking about.

Candy bounced into my office on the first appointment, a vivacious, very pretty teenager. She was trendily dressed and very voluptuous. When she walked down the corridor, heads turned, although she appeared completely oblivious to the attention she attracted. She seemed a typical happy-go-lucky adolescent, until she began to speak. Although she was glib, her vocabulary was extremely concrete; she sounded like a very excited 6 year-old. She could not express complex ideas or go into the "whys" of her actions. She tended to use other people's words and phrases with little comprehension of the underlying meaning. If I hadn't known Candy's history, it would have been too easy to believe that she really meant what she said. To her detriment, she talked like she knew what she was doing. Only by examining her behaviour was it possible to see that Candy had no idea of how to function in the situations in which she found herself.

Candy discussed all aspects of her life very freely. She seemed to have no awareness of what constituted personal, or "private" information.

With a few exceptions, she made no attempts to confabulate or fabricate her history although she did like to exaggerate to some degree. Despite this, she was completely ingenuous and it was too easy to tell when she was making things up to try to impress me. Her eye contact was too intense. She said things like "I'm not making this up...this is for real." It was like watching a five year-old with her hands in the cookie jar, trying to pretend she wasn't doing what she was doing.

Candy was fidgety, restless, and hypervigilant. She could not stop herself from looking out at the view of the parking lot and the airport runways which could be seen from my office windows. Her answers during the formal assessment were often punctuated by comments about someone's attire or a "hot" car below us. It was very difficult to keep Candy on task, even during the interview. Her attention span was extremely short and she bounced up and down in her excitement whenever a flight arrived or departed.

Candy confirmed the information I had already gathered from her social worker. She was in a special education high school program where she had considerable difficulty with math and spelling. She didn't think she had as many problems with reading but did admit to ongoing struggles with comprehension and sight word vocabulary. Candy indicated that she often daydreamed in class and her impulsive actions usually led her into conflict with her teachers or her peers. She couldn't focus in group discussions and also had difficulty controlling her temper. Despite her volubility, Candy reported that she did not like to talk because she forgot the topic, couldn't

explain herself, and did not have the words to say what she wanted.

Candy had attended at least six schools in the elementary grades, where she was in special education programs. She thought that this educational transience was instituted by her mother, whom she described as having a long history of alcohol abuse. Candy indicated that she hated to move when she was a child because it made her nervous and being nervous made her angry. Candy was also moved between Alberta and Ontario during the period she lived with an aunt who had taken her in when her mother was unable to care for her. Candy recalled that her mother was often physically abusive to her and hit her "all the time". She was kicked and locked in a closet by her stepfather, who also beat her with the buckle end of his leather belt.

Candy lived with her mother from birth to age seven, but then lived with her aunt from age seven to twelve. She next lived with her grandmother from age twelve to fifteen but began to have difficulty coping with the restrictions of family life in early adolescence. She was placed in group homes, beginning at age thirteen, whenever her grandmother couldn't manage her behaviour. Candy was on Ritalin, a drug commonly prescribed for children and adults with attentional disorders, from age seven to twelve, when she lived with her aunt. When she went to live with her grandmother, she was taken off the medication at her grandmother's request. Candy remembered that she began to get into trouble after the medication was discontinued.

Candy's adolescence was marked by a lengthy involvement with the justice system because of incidents of assault, break and enter, theft, and her inability to comply with court and probation orders. She had been in the Edmonton Young Offenders' Centre and was also placed in a youth detention centre in Calgary. She had committed other crimes, such as driving without a licence and automobile theft, for which she had not been caught. Many of Candy's arrests were a result of her inability to stand up to her peers. She was easily persuaded to engage in criminal acts, especially theft. She had also begun to prostitute herself at the age of ten, to support a "boyfriend" who lived off her earnings from the street. Candy still turned tricks whenever she ran away from her current group home, and it was easy for the other "girls" to talk her into returning to her old lifestyle. She knew many other young prostitutes and liked the easy camaraderie and seductive dangers which are integral to life as a juvenile prostitute.

Candy was not on any type of birth control medication but gleefully plunged her hand into the pocket of her leather jacket, spilling a fistful of wrapped condoms on my desktop. "These are what I use", she said. "I don't like taking pills". I later confirmed with her youth worker that she was given the condoms at her group home. Her worker was sure that she was "tricking" again and, as she was powerless to stop Candy from prostituting herself, she could at least ensure she had access to some form of protection from pregnancy or sexually transmitted diseases. Candy had been tested at least three times for the virus which causes AIDS. So far she had been lucky, as far as she could remember. She wasn't sure. She was, however, delighted

that she had not been pregnant, yet.

Candy remembered some details of her health history. Despite her history of respiratory problems, breathing difficulty, and asthma, she smoked about a half a package of cigarettes each day. She had back pain although she could not remember what might have triggered this. She cracked her ribs in a fight with another girl approximately two weeks before our first meeting. She apparently went to the Royal Alexandra Hospital for this, and she was a frequent visitor to its emergency department. Candy also apparently broke her kneecap after falling down stairs but reported that most of her injuries, such as black eyes, were the result of physical fights with other young women. She remembered at least two incidents where she hit her head and lost consciousness but she could not recall what had happened; each time she had been under the influence of drugs.

Candy began to use drugs and alcohol at a young age. She was using hashish on a regular basis by age twelve and moved on to cocaine when she was working as a prostitute. She had the drinking pattern of a seasoned alcoholic; she drank until all available liquor was gone and had been taken to the hospital for alcohol poisoning at least once. Candy drank almost every weekend and thought nothing of finishing a whole case of beer herself. She had experienced alcohol blackouts where she could not remember what she had done or where she had been. She emphatically stated that she was no longer using drugs or drinking now that she was in the group home, but I was quite sure that alcohol and drugs played an important part in her frequent

weekend absences. Candy was a very poor liar. Her demeanour was too earnest; her eye contact too intense.

Candy said she was scared all the time; scared to be alone, scared to be with people, scared to go to school. She knew she could not manage the demands others placed on her and worried that she could not understand what they wanted her to do. She said, "I shake all the time" and she had also developed problems breathing, a racing pulse and rapid heartbeat, and feelings of lightheadedness whenever she was frightened. Her symptoms sounded very much like a panic disorder. Candy was afraid to sleep at night as well, and linked this to a previous sexual assault where her stepfather's friend had raped her when she was not yet three. She also was afraid to dream because she thought she would remember her mother hurting her.

Candy thought she was too fat. To control her weight, she had learned to vomit on cue. She didn't even need to stick her finger down her throat anymore. All she needed to do was think about throwing up, and she did. She thought this was a neat trick. Other girls she knew didn't have the control she had. Candy had also struggled with anorexia and would not eat for days at a time, trying to lose weight. She did not think there was anything wrong with either the vomiting or the anorexic symptoms because she was "fat". If she wasn't fat, she wouldn't have to do those things. It was just that simple. When she wasn't fat anymore, she would stop.

Candy had tried to kill herself at least twice. The first time, when she

was eleven, she slashed herself with a razor blade. The second time, she tried to jump off a bridge at age twelve. She reported that the police had stopped her each time. but I wondered about this. Again, she was too earnest and forthright. She was honest, however, when she talked about her reluctance to discuss certain topics. She worried that she would cry and crying was a sign of weakness. In her world, if you were weak someone stronger would come along and make your life even more difficult. Like many others in her situation, she had learned to shut off her emotions, except for the ones which made her feel powerful, dangerous, and safe. Weeping did not accomplish anything for Candy. There was no time for sadness or loss; no benefits to dwelling on the times she had been mistreated, abused, or denied.

Despite her history of suicide attempts, incarceration, and involvement with Child Welfare, Candy could not remember a time when she had participated in counselling or psychotherapy. When asked if this might be helpful for her, she laughed. She did not think that anyone could possibly understand her. She also did not believe that others were trustworthy and so she would not want to talk to someone about her troubles. She seemed to forget that we had been talking about the intimate details of her life for approximately three hours.

Candy's goals were to get a good job and to stay out of trouble. She wanted to be a lawyer because she knew what lawyers did. She had had several appointed by the courts for earlier charges. Candy did not know how one became a lawyer but she knew that they wore nice clothes and did not

have to work outside on the streets in Edmonton's bitterly cold winters. Those were reasons enough for her. Candy also wanted a baby because she wanted someone to love her, "just because". She thought she would wait a bit, however, because she didn't have a steady boyfriend right then.

Candy sounded like a six year-old because that was the level at which she functioned. Her academic skills in reading, spelling and math calculation were all at or below Grade 4. She did not know her basic multiplication or division facts and therefore could not perform more complex operations involving two or three-digit numerals. She could not add or subtract with regrouping or solve equations involving fractions. Candy's reading skills were equally poor and she seemed to read only by sight. She had no word attack skills with which to decode unfamiliar vocabulary. Candy's intellectual functioning was significantly below others her chronological age. Although she did not look mentally handicapped, she clearly was. Her adaptive behaviour skills were extremely dysfunctional but, to many of the professionals involved in her care, she looked like she should have known what she was doing. Consequently, she was labelled a behaviour problem; a "hard core" kid who did not respond to any attempts to help her. Professionals washed their hands of her. She didn't follow through. She was ungrateful. Candy wasn't ungrateful, however, she was mentally handicapped. She did not follow through because she did not know what she was supposed to do. She could mouth the words but did not understand what they stood for.

I set another appointment for Candy so we could continue with the assessment but she did not come. The week before our next visit, she ran away from the group home. Her worker had strong suspicions that she was working the Drag area again, the section of the city where most of the street prostitutes congregate. We took turns driving those streets on our way home, trying to spot that familiar face and flaming red hair but our hours were not those of the girls who worked there. We started work in daylight. Their "jobs" did not begin until dusk. We played a "cat and mouse" game with Candy for several weeks, one that she was much better at than we were. We had time and the police on our side, however, and eventually Candy was picked up by the police for soliciting. She was placed in secure treatment at the Yellowhead Youth Centre, a local detention centre for adolescents in trouble with the law or unable to cope in less structured treatment facilities.

Candy came back to my office, accompanied by another worker trained to make sure his charges did not run away while out at appointments. Gone was the flamboyant, irrepressible, bouncy adolescent, replaced by a subdued, sullen, frightened child who cried throughout most of our appointment. She sobbed out her frustration and anger at losing her freedom. She could not understand why she had been put into "lock-up". She didn't think she had done anything so bad, and she really hadn't. She had merely returned to one of the few accepting groups she had ever known and to a way of life at which she was successful.

We talked again, and Candy told me that she had indeed been

prostituting herself, giving her money to two female "friends" who kept it for her. She had no idea of how much she made each evening, partly because she never kept it, but also because she could not count very well. Her "friends" kept her well supplied with cocaine and told her that she had to earn at least one hundred dollars each evening, because that's what her drug habit cost. Candy likely made much more than that but then, she would not know.

One of the few times she smiled was when she talked about her new boyfriend, who worked at a local hotel, in the bar. She first told me he was nineteen but then sheepishly admitted that he might be closer to 29. She denied that she was working for him and stated indignantly that he wasn't like that. She vehemently declared her love for him and told me that she missed him now that she was in secure treatment. He had never visited her there, even though she could have visitors, and she worried that he had found another girlfriend to replace her. Candy said she loved him but she didn't know his last name.

Candy drew sad little pictures of herself and her life for me (See Appendix C). She railed against life's injustices but could not see how her actions were related to the loss of her freedom. She thought everyone was persecuting her, although she did not use those words, and was sure that we all hated her. If we loved her, we would let her do what she wanted. Love, for her, was when there were no restrictions; no obstacles to her impulsivity and impetuosity. Love was a man twelve years older than she, with no last name.

Love was two "friends" who pimped her out, kept her earnings, and fed her a steady supply of drugs.

Candy told me about a friend of hers, not herself but a friend just like her, who wanted to be adopted by someone like me. She wondered how someone just like me would go about adopting someone like her friend. Could I adopt this girl who was just like Candy, but not Candy? She was just wondering, she said, because she had told her friend who was just like her, how nice I was. It wouldn't be for long, she said, because her friend was just the same age as her and when she turned eighteen, she could be on her own. It would only be for a few months. Her friend could have a mom and that would be nice. Her friend hadn't had a mom for a long time.

I knew, however, that there was no "friend" and that Candy was making a plea, as subtly as she knew how, that I take her away from the mess she had made. I also knew that I could not do that. I told her that I couldn't be her mom, even though I really liked her, and held her while she sobbed.

When she left my office, it was my turn to weep. I closed my office door and cried for a young girl who had to cope with situations she could not possibly manage; a child condemned to live on the outskirts, finding her support wherever she could through no fault of her own. I wept for all the young girls like Candy, looking for their mothers in the offices of strangers.

Wanda's Story

Wanda was initially referred to my office because of a history of learning difficulties and her social worker wanted to know what type of support she would need when she returned to school for academic upgrading. It soon turned out that Wanda was also experiencing considerable difficulty parenting her two young children, aged three and not quite one. She was unable to maintain a stable, healthy environment for her children and her own background was extremely troubled. The social worker spoke of years of involvement with Child Welfare and with various community and government agencies. She had had at least one previous assessment and many sessions of individual counselling for the issues arising from her very dysfunctional family of origin.

Wanda was very fragile and delicate. She had a shy, quiet demeanour; she smiled hesitantly and glanced at me out of the corners of her eyes. She reminded me of a small, wild thing in the wrong setting; like the yearling deer which wander into our city each spring and get trapped on the freeway; frozen in the headlights of oncoming traffic, unable to move to save themselves. The sparrow bones in her wrists shone under her skin. Wanda looked like a 13 year-old. She was 17.

At our first meeting, Wanda's social worker brought her into my office. She would not have been able to find my office on her own. Her social worker was very concerned, not only about Wanda's children, but also about

Wanda herself. She brought with her a file folder full of papers documenting Wanda's lengthy involvement with Child Welfare and Social Services. There were two separate Information Consolidation forms, the documents used by social workers to describe pertinent case details, covering approximately seven years of departmental concern. There was also a 7-page assessment, conducted when Wanda was 11. The social worker indicated that I would probably be subpoenaed for this case; asked to testify in court as to Wanda's competency to parent her young family. She thought that Wanda was trying hard but had neither the support nor the skills to learn more appropriate ways of providing for her children. Both children had been temporary wards of the government and in foster care for some weeks but were now back at home with Wanda.

The social worker told me that Wanda's apartment was "Condom City". Used condoms littered the living room and the bedroom where Wanda slept and probably worked as a prostitute. Her oldest child played in rooms filled with the discarded refuse of his mother's clients. Her youngest child was unable to crawl yet and had not made any attempts to roll over. He spent his days propped up in a beanbag chair in the corner. He was fed in the chair and he slept in the chair. He never cried or complained, but then, he never smiled or made the typical "pick me up" overtures that most 10-month old infants did. The social worker mentioned that Wanda had drunk heavily and used drugs throughout both pregnancies. She whispered the words "Fetal Alcohol Syndrome" when talking about the children, but not when talking about Wanda.

In my office, Wanda was very quiet and subdued. She had been through this procedure before and it had not changed her life in any substantial way. She was there because she had been brought there; because an assessment was part of her court order. She did not like it but she did not dislike it. It was just one of those things that she had to do.

We started off talking about where Wanda had gone to school. She remembered that Grade 1 had been in Winnipeg, but she had been born in Ontario. She had been placed in foster care at birth because her mother was "drinking too much". Wanda felt her mother still drank too much and had no respect for her or her children. When her mother moved to Alberta, Wanda attended a local inner city elementary school for Grades 2 to 6. She had then enrolled in another inner city school for Grade 7, where she finally got some special help for her problems with reading, math, and spelling. Wanda also had difficulty with attention, concentration, and restlessness. She could not remember much of what she had learned in school and also had trouble recalling names and the phone numbers of people she knew well. Wanda dropped out of school in Grade 8 and tried to go back but this didn't work. She tried Grade 8 another time, but was again unsuccessful. In between her Grade 7 year and first attempt at Grade 8, Wanda attended a local alternative education program for pregnant and parenting teens. She gave birth to her first child at age fourteen. She had her second child at age sixteen. In between those two pregnancies, she had an abortion. Apart from one year, she had been pregnant every year since she turned thirteen.

Wanda wanted to be a secretary when she finished her schooling. She talked about academic upgrading but didn't know where she could find the courses she needed to complete her education. She didn't know the courses she was missing because she couldn't remember much of her childhood or early adolescence. Wanda also wanted to play golf but didn't think this was the best way to make a living. When I asked her if she had ever played the game, she said that she had tried a computer golf game and was pretty good at it. She had never held a club or swung at a ball. She did not think her lack of experience would be a problem.

Wanda had begun working as a prostitute at the age of 12. She had been recruited by two "friends" who showed her how easy it was to make money on the streets. She had worked regularly for about two years, but had recently been caught. She had spent one night in detention and was sentenced to six months probation. She was quite emphatic that she was no longer working. The professionals involved in her care were equally emphatic that she was. Wanda stated that she now got money from her mother and her brother, and didn't need to turn tricks anymore. I knew, however, that her mother had no money either; the social worker had told me that Wanda was likely maintaining her extended family on the money she made as a prostitute. At the age of 17, she was supporting her mother and at least three of her four half-brothers, all older than her, by selling herself on the streets each night.

One of her half-brothers, each of whom had different fathers from

Wanda and from each other, had served a jail sentence for sexually abusing Wanda when she was a child. The abuse had finally stopped when she was pregnant with her first child at age fourteen but had lasted for eleven years and it was quite possible that her half-brother had been the father of her oldest child. He was convicted and sentenced to 30 months in jail but, when he was released from prison, Wanda's mother allowed him back into the family home. This was her son. He was "family" and she couldn't abandon one of her children. She didn't seem to realize that she had abandoned Wanda by taking her abuser back. The sexual abuse began again and continued until Wanda left home for good, taking her two children with her. Wanda could also remember other sexual assaults and rapes, sometimes by her brothers' friends, other family members, and sometimes by "bad tricks". She could not remember the number of times she had been raped and wasn't even sure what rape was, anymore. She had numerous episodes of sexually transmitted diseases which, thus far, had responded to antibiotics. She had been checked for the virus which causes AIDS at least three times and the test results had been negative, as far as she knew. According to her file, however, Wanda had contacted Child Welfare on at least two occasions in the past, in a panic because she thought she was HIV-positive. She was going to have another HIV test in a month, which was, to me, another sign that she was likely still working the streets.

We talked about Wanda's health history and she told me that she was in hospital as an infant because she had surgery on her head. She had a scar which ran transverse across the top of her skull, connected by two "soft

spots" above either ear. She had no idea why the surgery had taken place. She could not recall any other hospitalizations, apart from the births of her two children. Wanda had not been involved in any automobile accidents but had been in many physical fights when she worked as a prostitute. She had been physically abused by a boyfriend as well.

Wanda remembered that she had begun to drink heavily at age 12. She could recall at least three alcohol blackouts after her first child was born and she spent one night in the emergency department of a local hospital for suspected alcohol poisoning. Wanda indicated that she did not drink as much now but she was still using drugs, including cocaine, hashish, marijuana, and LSD. She began abusing substances at age 12. She denied that she had used substances or alcohol when she was pregnant and said she had always quit using as soon as she knew she was pregnant. I wondered about her ability to be aware enough of her body to detect the early stages of pregnancy. She might have not even known she was pregnant until close to the end of the first trimester. She could have had eight to ten weeks of hard drinking and substance abuse before she knew enough to stop, if she had.

Wanda told me she didn't really have any trouble sleeping, but the babies kept her awake and she was often very tired. She had trouble sustaining the necessary energy to cook three times a day and I wondered about her ability to prepare meals for her children. She had told me she could not bother to eat, herself.

Wanda was depressed and she cried easily and often. She did not notice any change in her depressed mood after her children were born and her low mood was constant and unlikely due to postpartum depression. Wanda, however, worried more about her anger than about her sadness. She often had difficulty controlling her rages, although she said she had never been angry in front of her children. If her children were not around, however, she became very physically violent and this frightened her a great deal. But then, most things frightened Wanda. She had panic attack symptoms, including shortness of breath, a racing and erratic pulse, and lightheaded feelings. She had several specific phobias and was also afraid to be alone. One of the only times she could recall feeling safe was when, as a child, she had stayed at a local women's shelter. She could sometimes achieve the same "safe" feeling in her own home, but this usually did not last, because she would be overwhelmed by panic again.

Apart from her goals to become a secretary and play golf, Wanda had few other plans in her life. She wished for a better life, a good family, and a good job. She might as well have wished for the moon. She had no idea how to achieve any of her dreams and, for her, these simple things were utterly unattainable. In Wanda's day-to-day existence, there were no similarities to link her world to the contented, middle-class life she saw on television. She was an outsider in her own country, separated from the commonality of shared experience by circumstances beyond her control.

I set another appointment to meet with Wanda but she did not come.

My phone calls to her apartment went unanswered and, when I finally contacted her social worker in desperation, I found out why. Not long after our first appointment, Wanda had phoned Child Welfare again, in a panic, unable to look after her two children. She had asked that her children be taken into care once more but the receiving social worker found her to be so distraught that all three of them, Wanda and her two children, were placed in care. Wanda disappeared one night, taking her oldest child, but leaving her youngest. She did not say where she was going or why she left. She made no attempts to contact her youngest son, who remained in foster care where his arms and legs were fractured in a beating by the foster care provider. Her family either did not know or would not say where she had gone. Wanda had vanished.

Her social worker kept me informed if anything new came up but for many months, Wanda was missing. Her oldest son was also eventually placed in foster care, after she could not manage the demands of raising even one child and gave him up, too. Wanda remained isolated and inaccessible for almost one year. She finally turned up again, when her children were to be made permanent wards of the government. She wanted her children back. She was a good mother. She had changed. She was now in a relationship with another man, but her social worker suspected that the new partner was her pimp, not her boyfriend. Both Wanda and her partner had the trappings of involvement in the drug and prostitution subcultures. Although they had no permanent address, they each had a cellular telephone and electronic voice mail to keep track of their customers.

Wanda was also pregnant again. When asked, she said she was about five months pregnant but she looked more like eight months, according to her social worker. She thought Wanda was lying about her pregnancy because she was frightened this baby would be apprehended as well.

I contacted Wanda by phone again and set another time to meet but Wanda did not keep this appointment, either. I eventually reached her three days after our missed appointment and asked her what had happened. In contrast to our earlier conversations, she was sullen and reluctant to talk. She hung up on me when I asked her why she hadn't shown up at my office.

The next time Wanda and I met was in court. She had a court-appointed lawyer to help in her defence but there was no one else on her side of the courtroom. Her family and her new partner had not come to offer support. Inexplicably, five minutes before her case was to be heard, Wanda fired her lawyer. There was no reason for this that anyone could discern and even the lawyer was dumbfounded. Despite her lack of counsel the judge elected to continue with the trial, and Wanda sat alone, with a yellow legal pad and pencil supplied by the Child Welfare lawyer in front of her.

I was the first witness. I stood in the witness box, delineating Wanda's shortcomings and failures as a parent. I talked about her language deficiencies, her emotional instability, and her consistently poor adaptive behaviour and all the time I talked, I was conscious of Wanda, sitting alone, staring at the yellow pad of paper and the pencil which would do her no good

because she could not spell. When the Child Welfare lawyer had finished her questioning of me, the judge asked Wanda if she had any questions in her defence. Wanda said "No", and I was dismissed. I left the stand, feeling miserable and guilty, aware that Wanda could not understand what the judge had asked of her; knowing that she could not even speak in her own defence, let alone ask another individual questions which might somehow bring her children back. I was free to go, but I have never been free of the memory of that little figure, swollen belly resting against the table, waiting for the inevitable all alone.

Wanda lost her children that day. They were made permanent wards of the government, to be swallowed up into the Child Welfare system. She would have no further contact with them. Her last chance to see her sons might be their appearance on a local television program for hard-to-adopt children. She had become a childless parent. Children without their parents are orphans. There is no word for parents without their children.

Sharon's Story

Sharon was different from many of the other young women whose paths led to my office. Although she, like so many of the others, did not find her way alone, this time it was her family that brought her to me. Sharon was still living at home, but "home" was with her paternal grandparents, whom she called "Mom" and "Dad". Her birth father also lived at home and, while she knew that he was her father, she reserved the term for her father's father. Her

father was merely "Jack"; like a brother, but much older. Her father's siblings were her siblings, too.

The precipitating incident which led Sharon's family to bring her to me was her impending eighteenth birthday. They were worried about Sharon's ability to make the decisions necessary for independent living and for competitive employment. They knew that she could not manage to live on her own. Sharon was equally determined that she could. Her grandparents were justifiably concerned that, if Sharon ran away after her July birthday, they could do nothing to help her because she would be seen as capable of making informed decisions on her own behalf. They thought, as did the rest of the family, that Sharon's actual abilities bore little relation to what she said she could do. They knew that she could sometimes talk like she knew what she was doing, but could not follow through with the concrete actions which would put their fears to rest .

Sharon's grandmother and her aunt came to the appointment with her. We talked first, while Sharon fidgeted in the anteroom, waiting for her turn. They told me about the circumstances behind Sharon's birth and how her birth mother had abandoned other children and other men before leaving Sharon and her birth father behind. They knew that Sharon's mother had been a heavy drinker, and had worked in a local bar up until a few weeks before Sharon's birth but did not know many other details. Much of what they knew had been pieced together from what they heard from other people in their isolated, small community after their son's relationship with this woman

foundered and he came home again. They had been estranged from their son during this relationship and only discovered that they were grandparents when Sharon was approximately 6 months old.

Her grandparents had fought a bitter court battle to legally adopt Sharon. They did not not think that her birth mother had wanted the child as much as she wanted to hurt them and their son. The legal fees had been very high and they had almost bankrupted themselves in their fight to gain custody of their grandchild. In spite of the costs, Sharon's grandmother declared that it had been worth every penny to keep this child out of foster care and at home with her family.

This family was a fierce advocate for its youngest, most vulnerable member. They rallied around her and fought to ensure Sharon got what she needed. They stood up to teachers and made sure that Sharon got special help when it was determined that she could not keep up academically. They surrounded her with love, support, and a blanket of security that shielded her from some of the hurts of a less accepting society. They had done a remarkable job in raising this unexpected child but they had not been prepared for the onset of adolescence. In spite of their best efforts, Sharon had gotten pregnant at the age of sixteen. The family talked this over and decided that a therapeutic abortion was the best option for Sharon and for them. To their credit, Sharon was also given a say in the decision and she opted for termination as well. Less than four months after the first abortion, however, Sharon announced that she was pregnant again. The decision to

terminate this pregnancy was also made, but this time the decision-making process was less supportive and more autocratic. Her grandparents and the other relatives were beginning to worry that Sharon would continue to get pregnant but, at age eighteen, their ability to control the outcome would be gone. Sharon could well have a baby that they knew she could not raise. Her grandmother told me in no uncertain terms that they were too old to go through this again. It had almost killed them the first time and they had simply run out of energy. Although they loved their granddaughter dearly, they were too old and too tired to be "parents" again.

Sharon's grandmother and aunt were very frightened. They were watching the child they had raised turn into someone they did not know. They were losing their ability to talk to Sharon and to influence her decisions. They were afraid that they no longer knew this child for whom they had fought so long and hard. She was turning into a stranger, an adult, without any of the skills necessary to function like one. She wanted the trappings of independence but could not manage the responsibilities which came with it.

In an effort to prevent any further pregnancies, the family had taken Sharon to a sympathetic local doctor, to arrange for injections which would render her infertile for up to four months at a time. They had actually wanted Sharon to be sterilised but knew that this procedure was not done now, except in the most exceptional of circumstances, and so had settled for the hormone shots. They had also explored other options but knew that there were few appropriate for Sharon. She was too careless and unreliable to

take birth control pills and condoms were of little use if one did not stop to use them. Their previous family physician was unsupportive of any birth control medications - Sharon's grandmother put this down to his strong Catholic background - and he had actually yelled at Sharon and her grandmother when he found out Sharon was pregnant for the second time. Sharon's grandmother was both offended and deeply humiliated by this. She already felt that both pregnancies were somehow her fault and the inappropriate moralising of this man who had cared for their family for years was a further blow to her self-esteem. She had been wounded by someone she had thought to be understanding and she could neither forgive nor forget his outburst.

I sensed that the concern over Sharon was dividing a strong and united family, the way it had polarised the medical professional in this small community. The strain was beginning to tell on them; Sharon's grandfather had had a stroke in the last year and his health had deteriorated. Sharon's grandmother now had two individuals to worry about at a time when many women her age were enjoying the independence which comes from having children who have matured into capable adults. Instead, Sharon's grandmother was thrust into the complicated task of parenting yet another adolescent at a time when she no longer had the stamina. The rules of parenting had changed and she had missed the years in between her own children's adolescence and her granddaughter's. She had been left behind and the skills which she had successfully used to raise her own children did not work on Sharon. Sharon was different and her grandmother knew it.

Sharon's grandmother expressed her concern for Sharon's social isolation. While she had some friends, these were not ones she would have chosen and she worried that Sharon was being negatively influenced by her peers. She talked about Sharon's mood swings, her anger, and her verbal disinhibition. In particular, she was very distressed by her granddaughter's swearing because she had never allowed her other children to talk that way. With Sharon, however, she could not control her with the conventional skills she had used in the past. No matter what she tried, there were no appreciable changes in her granddaughter's behaviour.

Sharon's grandmother also told of a number of Sharon's physical problems, including a "lazy eye" where the muscles in one of her eyes did not work properly and allowed the eyeball to drift inward toward her nose. Although this is easily corrected by surgery, it had never been done. She also talked about chronic back pain but this had never been investigated and she thought that Sharon might be making some of this up to avoid doing chores. She did not know about scoliosis, which is often present in FAE-affected individuals. Her aunt and grandmother also discussed Sharon's complaints of sore joints and muscles but also attributed this to exaggeration rather than to any actual physical problems. They remembered that Sharon was very motorically and linguistically delayed when they finally adopted her and was almost five years of age before she started to talk. They also discussed her inability to pay attention, sit still, and stay focussed. They thought it odd that she could remember all the little inconsequential details but could not see how these details fit together into a pattern.

When it was Sharon's turn in my office, we talked about many things, including her schooling. She wanted to go to college but she didn't think that she needed to complete her high school education first. She said that she often skipped her classes as school was not a good place for her to be. Sharon told me she had been retained twice in Kindergarten and by the time she finished Grade 1, she was as old as most Grade 3 students. She said that she hated school and didn't like doing her homework. She got special help in school but hated this too, because it made her different from her classmates. Sharon did not think she had any difficulty with math, although she couldn't manage money. She also thought her reading skills were good. Sharon said she couldn't remember information if it was presented too quickly and could not remember how to do things that she had done before. This often got her into trouble at home because her grandmother would think that she was deliberately refusing to do something, when she actually could not remember how. Sharon told me that she often forgot to do her chores and then had to make up excuses when confronted by her family.

Sharon did not clearly understand her strengths or her weaknesses but knew that she would soon be eighteen and the world would then be hers to hold. She could not contemplate the possibilities which might arise if she left her home and supportive family to live independently. Sharon talked about how hard it was to say "no" to her boyfriend or her friends, especially when they wanted her to do something wrong. She was completely vulnerable to peer pressure, a frightening prospect for the family who had tried so hard to protect her.

Sharon was as artless as a child, despite her two pregnancies. She had not been toughened, embarrassed, or made self-conscious in any way by being pregnant. Being pregnant was something that many of her acquaintances had done and one of her best friends was a pregnant fifteen year-old. If Sharon wanted to "fit in" with a peer group, teen pregnancy was a guaranteed initiation rite. She could just be "one of the girls" discussing morning sickness and stretch marks while she finished her math homework on the school bus each afternoon. She would not be alone in this, as she had been in so many other aspects of her life. She could be one of the "in crowd" who proudly sailed through the hallways at school, their pregnant bellies carving through the crowd.

Sharon admitted that she was confused and frightened about her future, and she wept at this point. She was worried about many things, such as driving a car, because she felt that everything went too fast. Sharon also confessed that she was afraid of dying but she didn't know why. She had never been sick and, apart from the two day-surgery admissions for the abortions, had never been hospitalized either. Her aunt and grandmother told me, however, that she had watched her grandfather have his stroke and perhaps her fear stemmed from this, but there was no way to know. She didn't think that anyone understood her but later told me that her boyfriend was the only one who felt the same way she did. She did not quite know what she wanted, apart from leaving school. She also thought that her family held her back and prevented her from doing things that other kids her age did.

Sharon thought she loved her boyfriend. She was not so sure if he loved her, but that didn't matter as much. The important issue was her feelings since she could not understand his. Her boyfriend lived with her family and she thought this was okay. Her grandmother was not so accepting but realized it was one of the few ways that the family could keep track of Sharon's contact with a young man she would likely see, whether or not they allowed it. Sharon's boyfriend was mentally handicapped and no longer in school. He worked in a supported employment position in a local business. Sharon did not know whether she wanted to stay with him or marry him but knew that she would be lonely without him.

We talked about Sharon's dreams and goals. She wanted to bypass the remainder of her Grade 10 year and then leap into the world of other eighteen year-olds, who were going off to school, leaving their families, and preparing to take their places in the wider world outside the tiny community she had lived in all her life. She wanted to be a massage therapist because she had a short work experience placement with a local practitioner and thought this job was easy. She also wanted to go to college, like most of the other eighteen year-olds she knew, but didn't know what she would do once she got there. She knew she wanted to get away but didn't understand what she was leaving or where she was going.

Although Sharon talked about going to college, her skills were extremely weak and well below other young women her chronological age. She could not read above a Grade 2 level or perform math calculations

beyond Grade 4. She had most of the diagnostic characteristics of a severe Attention Deficit Hyperactivity Disorder, including great difficulty with attention, concentration, distractibility, and physical restlessness. Her functioning placed her within the Mentally Handicapped range and, although she sometimes sounded like she knew what she was talking about, this didn't happen often. Like so many other adolescents and adults with FAS or FAE, she only sounded competent. She did not have the actual skills to carry out much of what she discussed and so she repeatedly set herself up to fail. People expected that she had the ability to formulate concrete actions based on her words, without realising that words were the only things she had.

The language Sharon used was a hodgepodge of what she had heard others say. She picked up phrases or vocabulary items the way other people picked up pretty pebbles on the beach. They were souvenirs of her encounters with others but they had no intrinsic meaning in and of themselves. They were only reminders that she had heard someone else speak. These words were not linked to awareness and therefore no action followed. For those who heard Sharon speak but who did not understand her underlying communication disorder, there was an assumption that vocabulary equalled competence. They did not know that, for Sharon, words were only a talisman against loneliness, devoid of meaning outside the context provided by the listener.

I wondered about this young woman and her family. How could I give Sharon the independence she craved while also providing the protection her

family so rightly knew she needed. Once again, there was a polarization of competing agendas, and I was called upon to be a mediator between factionalized parties. Unlike most of the work I did with FAS and FAE-affected individuals , however, the polarization was not between agencies or government departments and the individual herself, but between members of the same family. Sharon's family wanted her to be protected and cared for. Sharon wanted to be free and she was incapable of understanding the price she might pay for her release.

When I met with Sharon, her grandmother, and her aunt again, another of Sharon's aunts came along. We first talked together, Sharon and her family, and I explained what I had found. Sharon did not understand much of what I said, apart from my gentle request that she consider returning to school to finish out the school year. She burst into tears, protesting that she could not return to school. She was too old. She didn't like it. She wouldn't go. No one could make her. She was right, of course. No one could force her to attend classes where she only felt more excluded with each passing year. The world was going fast and faster and she could only watch helplessly from the sidelines as younger students caught up and then passed her by. I could not blame her for wanting to call a halt to the continual frustration.

When I asked Sharon if I could meet with her "mother" and "sisters" alone for a few minutes, she leapt at the opportunity. This experience was too intense for her. The words were too big, in spite of my efforts to explain things simply and concretely. There were too many witnesses to her discomfort.

She did not want to hear that she could not do things. She already knew that and was hoping for "good news". I had not delivered this and she could not participate any longer. She stormed off to sit in the waiting room and drink cup after cup of very strong coffee.

Sharon's grandmother and aunts were embarassed by Sharon's behaviour. They tried to apologize, saying that this was what they went through each day. Tears, rage, door slammings, swearing, and emotional lability were commonplace occurrences in their home. Sharon's grandmother likened it to living with a volcano. The family knew it was there but tried to pretend that it wasn't; doing their best to ignore the seething, rumbling presence in their lives. They tiptoed around Sharon, hoping that something wouldn't set her off, hoping that they could get through the day without an explosion. They more they tried to ignore the problem, the worse it became and Sharon's grandmother and aunts had reached a point where they could not go on.

With Sharon absent, it became easier for me to make my recommendations as I no longer had to couch everything in careful, concrete language. I talked about Sharon's need for support in most aspects of her life, including employment, sexuality, independent living, and socialization. I agreed with their concern about Sharon's ability to earn her own way through competitive employment. We talked about the stresses which Sharon unknowingly placed on other family members, especially her grandmother. I agreed with their reservations about her capability to manage all the

intricacies of independent living although I also felt that she could no longer live at home. I told Sharon's grandmother that no one would blame her if Sharon moved into a supported living situation. She had done an excellent job in raising this child who was so different from all the others. No one could point a finger at her and tell her she had failed. At this, Sharon's grandmother burst into tears. This was a secret fear, that others would see her as the cause of Sharon's weaknesses, fanned by the uncaring words of the family physician who had summarily accused her of failing in her responsibility to monitor the actions of a child who was no longer a child. We sat there, four women, trying to plan the life of another woman who was one of us only by virtue of chronological age.

I told them of supports within their community and explained the steps required to make application for a supported living situation. This would allow Sharon to live away from home from Monday to Friday, and return home for Saturday and Sunday, if she wished. While she was living away from home during the week, she could participate in a local supported employment program where her strengths rather than her weaknesses would be the focus of treatment. I also discussed the possibility of enrolling Sharon in a structured employment training program for individuals with lower cognitive functioning. Although this program was not offered in their community, it would give Sharon an opportunity to go to college like others her chronological age. She, too, could go through the rites of passage which surround the act of leaving home to go to school. She could buy her metal trunk and new school wardrobe, apply for college, and hold her head high

when the subject of further education came up. She would be like her peers. She would fit in.

I talked about the need for formal guardianship and trusteeship for Sharon and told them about the government agency that could help them establish these supports. I knew that Sharon was too easily led, too gentle and trusting to possibly discern the machinations of those who might wish to harm or take advantage of her. She had the potential to be like so many of the other young women I had worked with, the ones unlucky enough to have no family to care. These abandoned young women were like the little metal ducks in a shooting gallery, doomed to go around and around forever, waiting for the next shot which would send them spinning and whirling on their pivots, forever connected to a track from which they could not escape.

Sharon's grandmother and aunts listened carefully to my suggestions. This was the first time anyone had offered them concrete suggestions which would free them from the burden of caring for a young woman who no longer wanted their support. They would still be there but others could share the strain. These were hopeful developments. They did not like to be constantly telling Sharon that she couldn't do this or that. They had began to see themselves as "nags", holding someone back who just might succeed in meeting the next milestone in spite of all the evidence to the contrary and her failure to meet every milestone at a rate consistent with others her chronological age. Although they knew that Sharon had many problems and that these tended to overshadow her simple strengths, they had lost their

sense of perspective. They had lived with Sharon and her difficulties for so long, they no longer knew what "normal" was. They had begun to doubt their own observations and the conventional sources of community support; the school system, their medical practitioner, and another psychologist, had not given them direct answers to their questions. A previous assessment had merely mentioned that Sharon was "doing the best she could" but did not say exactly what that meant. Her teachers had told them Sharon was "making progress". Platitudes flowed from everyone but this family wanted truth, not comfort. That they could provide for themselves when they knew what to expect.

In my last contact with Sharon's family, I heard she was preparing her application to attend the structured college program in January, 1997. Sharon had moved to a supported therapeutic living situation where she had an apartment, a roommate, and several support staff who ensured she was able to manage the day-to-day routines of laundry, shopping, and meal preparation. She was working three days a week in a supported employment setting and doing very well. She still struggled with frustration, emotional lability, the limitations imposed by her language weakness, and her Attention Deficit Hyperactivity Disorder but these were being appropriately managed by the trained staff in her work and living situations. These men and women anticipated problematic incidents and worked quietly behind the scenes to ensure that Sharon was not confronted by insurmountable difficulties. While the anger was still there, she was able to go home to her family on the weekends and talk about her job, her apartment, and her new friends. She

was like her "sisters" who had left home to return with stories of success and triumph. She had found a place for herself within the wider community, supported in her drive for independence but not pushed to be what she could not.

CHAPTER SIX

Gathering the Threads

As I wrote the stories of the five participants in this research, I was struck over and over again by the similarities of their lives. Certain patterns seemed to repeat themselves, even when the circumstances of the participants were very different, leaping out to catch my attention. I found it increasingly difficult to focus on the individual and the stories began to blur one into another, like water colours on wet paper. If I was close enough, the stories became distinct but if I stood back in an attempt to gain distance, they blended into something different once again. It was frustrating, this kaleidoscopic change, where the pieces together were different from the pieces apart. I began to understand some of the frustration that my participants felt when the fragments of their lives somehow never added up to the same "whole" more than once.

Many of these shifting patterns were rooted in a sense of powerlessness where each woman felt that her life was in the control of forces larger and stronger than herself. She was buffeted by the relentless actions of others who never gave her the time to make her own decisions. It was as if she was shouting into a wind so strong that it carried her words away before they left her tongue. She could not hear herself speak and there was no quiet time for her to listen; the wind never stopped blowing. She learned to shout out her needs through her actions and the ones which

caught my attention were the same ones which got her into trouble, over and over again. I was forced to go past the obvious and to search out the small distinctions which gave each woman back her individuality. I had to close my eyes and conjure up the faces of the women I worked with, to ensure that they remained separate from each other.

Education

With the exception of Sharon, each of these young woman was no longer in school. Even Wanda and Candy, the young women in late adolescence, did not attend classes. Wanda had left school at age 14, after the birth of her first child, and each of her subsequent attempts to return had been unsuccessful. Candy, who had been a sporadic attender in her special education high school program, was no longer in school because she had been placed in a secure treatment facility. Janice had not been in school for several years, although she had also unsuccessfully tried to return to a local high school. Sherry and Grace also had not been in school for many years, although both had tried various upgrading and employment training programs at different stages in their lives.

Each of these young women had a clear understanding of her educational weaknesses. Each usually knew what she couldn't do, although she did not understand the depths of her difficulties. She knew that her math skills were often the weakest subject area and that spelling was often the strongest. She also knew that she could read, albeit at a very basic level, but

could not understand what she read. Each understood that her skills were often unevenly developed and knew that her teachers were usually frustrated with her inability to transfer knowledge from one situation to another. In reading old report cards and cumulative file material on each woman, I also understood that this inconsistency caused many teachers great consternation because they did not understand that there were clear distinctions between the things she could do and the things she could not. Each young woman knew that she did not pay attention very well and that she was easily and frequently distracted in group settings. She knew that she could not sit still. She knew that language was not her strong suit and that she was often lost in others' words, especially if they talked too fast, used complex vocabulary, or did not explain themselves. She also knew that she could not write down what she wanted to say, despite her relatively strong spelling skills, because the words did not make sense when committed to paper.

Without exception, the participants had few positive memories of their school experiences. Their remembrances were primarily negative although they could recall the names of teachers who had been kind, because there had been so few of them. Mostly, they remembered the people who had not helped them or who had punished them for being who they were. They also remembered the frequent moves during their school years. Some, like Candy, attended different schools for each grade during their elementary years. Candy first learned to hate any kind of change at this time, stating "I hate moving...I hate change...it makes me nervous and makes me mad...". Janice could only remember the first school she attended. The details of the

years between Grade 1 and Grade 8 were gone, wiped out in a dissociative haze. Wanda, Grace, and Sharon were lucky, attending the same school for all their elementary grades. Despite this stability, Sharon had few kind words for her educational experiences, saying "...school is not a good place for me to be...".

Each woman could recall humiliation at the hands of teachers, support staff, principals, or their peers where their faults were placed on display for all to see. They remembered the times they were the recipients of corporal punishment for failing to sit still or for being unable to concentrate. They told of being put into corners for what seemed like hours, while their classmates went on with their lessons. They spoke of the shame of not learning and of not being expected to learn.

Each woman saw herself as a problem, rather than as a successful learner. Each knew what it was like to have special education assistance and they had all been in some type of special class, ranging from partially integrated, pullout programs for core academic subjects to totally segregated classrooms. To a person, they hated it. In their eyes, it made them different; seperating them from their peers at a time when they desperately wanted to be just like everyone else. There was a stigma to being in special classes that outweighed any possible benefits. They were so humiliated at being singled out yet again, that many of them simply gave up. They stopped learning because special classes were for "dummies". If they were in such a setting, it was because they were stupid and, if they were stupid, there was no

sense in trying.

Each of these women desperately wanted to have the same lessons as their peers. They did not want the watered down instructions or colouring sheets that they could recall being given, instead of the regular math or language arts assignments. They knew that they were not provided with the same materials as their classmates but they did not know why. They also did not know why they were subjected to psychological or educational testing. Each spoke of the times she was taken from her classroom to be put through yet another battery of assessment instruments, without any explanation of why she was singled out for this special treatment over and over again. The results of their assessments were never explained to these young women, even when they were adolescents, and their own intuitive understanding of their strengths and weaknesses was never confirmed. They were never consulted - never considered as partners in the educational process - and they believed that their input was not valued. These women were not asked to share their experiences and so began their formative lessons in becoming voiceless.

These young women were the children who stopped talking because no one listened. One of the first things they had learned at school was that they had no right to speak, or at least no right to speak when they thought it important. They could not master the unspoken lessons governing when it was appropriate to converse and when it was not. They were censured for speaking out and then for acting out when language was denied them. They

learned that, for them, actions spoke louder than words because their words were never heard. They learned the benefits of the grand, exaggerated gesture, of a larger-than-life personae, of being loud, confrontative, and angry. They learned to mask their feelings with behaviours which kept them safe by keeping others at bay. They learned to run from problems and quitting school was infinitely better and less damaging than the continual confrontation between their dreams of success and the reality of failure.

The recollections of these women's school experiences echoed the information gathered by Streissguth, Barr, Kogan, and Bookstein (1996) in their work on secondary disabilities in individuals with FAS and FAE. The same problems with memory, attention, and math skills which these five women described were mirrored in the information collected by Streissguth and her colleagues. They shared the problems with disrupted school experiences, defined by Streissguth and her colleagues as suspensions or expulsions from school, or early school leaving. They had the same pattern of attention disorders, repeatedly incomplete school work, grade retentions, problems with peer interactions, and disruptive classroom behaviours as the subjects in this research. The experiences of these five women were not unusual, when placed within the wider context of scholarly research conducted with other similarly affected women in another urban setting, in another country. These similiarities cried out even through the bar graphs and statistical tables of a quantitative research approach, and I wondered about the stories these other people might tell, if given the opportunity.

Poverty

With the exception of Sharon, each of the women I met existed on the outskirts, her life marginalized and demeaned by the constant grinding presence of poverty. Most of these women had not worked competitively for more than a few weeks at a time and some, like Wanda, Janice, and Candy had never worked in the competitive labour market. Sherry, Wanda, Janice, and Candy had come from families were Social Assistance payments were the only income and reliance on governmental support was an accepted method of earning a living. Each of these women could care for herself or her family on Social Assistance because it covered the little things, such as health and dental care, that minimum wage jobs did not. Each young mother knew her children's basic needs could be met if she did not work, and there were no advantages of leaving a system which at least kept her children fed, clothed, and in good health. Each of these women talked about the experience of being on Social Assistance with its attendant humiliations; reporting to a social worker about the intimate details of their lives, having to account for where their meagre support payments went, or feeling like they were somehow worthless. They all wistfully talked about how wonderful self-sufficiency would be, but had no concrete plans which would encourage their own independence.

Although Social Assistance benefits were certainly better than nothing, it was not much better. Even the most competent of comparison shoppers would be hard-pressed to feed a young family on the money provided by

Social Assistance. Fresh fruit and vegetables, milk, and meat were luxury items; macaroni and cheese, pizza, and convenience foods made up the bulk of the meals prepared by each of the participants in this research. These young women could not read well enough to follow a cookbook and, even if they could, they could not afford most of the ingredients. They tended to prepare the same meals over and over again; packaged macaroni and cheese dinners, hot dogs and fried ground beef, cold breakfast cereals, and bread and peanut butter, were what they told me they served. Milk did not make a regular appearance because it was too expensive and spoiled too easily, so cold cereal and packaged macaroni and cheese were made with water. Fruit juice prepared from frozen concentrate was also a rarity, but not necessarily because of cost. It required preparation and these women had not developed the forethought required to defrost frozen juice. They would have to anticipate that their children would want juice, defrost it, and then make it; a three-step process. They could not manage this complexity. If their children wanted juice, they gnawed it from the cardboard tube, still frozen.

Because these women did not have any other method of transportation beside public transportation or rides from friends who might have their own vehicles, they were limited in their ability to shop for bargains. Spending four hours on a bus with two young children to save seven cents on a box of laundry detergent was not a savings. What passed for shopping was often done in neighbourhood convenience stores with high mark-ups, limited selection, and an emphasis on the high starch, high fat, prepackaged meals which fill one up with empty calories.

Each of these women, with the exception of Sharon who still lived at home with her family, was a regular user of local food banks. Sherry, Wanda, and Janice did not know how to budget their limited financial resources to make their grocery dollars stretch to their limit. They often lined up at the door of various community agencies or churches with other poor families at the end of each month, trying to get enough food to make it to the next cheque. With their limited problem solving skills, these young women might spend twenty-five dollars on a cab ride to pick up two bags of groceries from a food bank, never seeing the irony in spending money to get something free. It would not cross their minds to spend the twenty-five dollars on food because, if they could get to the food bank, the food was free. Why pay if they could get something for nothing? They did not factor the cost of the cab ride into the cost of obtaining the groceries. These two things were different because food was food and cab rides were cab rides. If they had the money for a cab, they would use it until the money was gone. They wouldn't worry about what would happen after that because each of these women could not see how her present affected her future. Things happened to them in isolation and there were no links to establish cause and effect reasoning.

Each woman had dreams of a better life where she was independent, free of the Social Services system, and had a job or a partner who could support her. She wanted to have her own house, not an apartment, where she could hang up pictures where she wanted. She wanted to be like the other women whose lives she saw on television and in the movies, who did not live in poverty. She wanted to be different than who she was, and the

same as the others who lived in circumstances she could only imagine.

Information provided by the City of Edmonton's Community and Family Services department (1996) supported the stories of these women. Data indicated that the urban poverty in Edmonton's metropolitan area ranked third highest among twenty-three urban centres in Canada. They, like 59% of other single parents in the city were identified as poor and, as women, they were poorer still. In the northest Edmonton area where most of them lived, more than 65% of their neighbours were classified as low income wage earners, and more than 40% were single parents as they were. More than 17% had less than a Grade 9 education, as they had. The areas where they lived were among the poorest in the city, with rates of low income families between 23.6% to 67.5%. These women, along with their neighbours, shared in the three-fold rise in use of the Edmonton Food bank over a ten year period. They were not exaggerating their poverty to gain fleeting sympathy. These women were truly poor, with few possessions, few prospects, and no hope of change.

Unemployment

Although all of these women had gone to school, each was illiterate and so they lacked even the most rudimentary of academic skills which might have helped them find employment. They could not read well enough to search through the daily papers for possible job openings. Some could not read well enough to decode the simple "Help Wanted" signs posted in

business windows. Even the most educated of the participants could not fill out an application form unaided. They relied on the good will of others to help them find work but, even if they were lucky enough to get a job, they were usually the last hired and first fired. They lacked the understanding that work was something that gave one's life structure and meaning. They also did not have the basic employment readiness and literacy skills to ensure that they could manage to keep the jobs for which they were qualified.

Although most of these women had been placed in government-funded basic training programs sometime during their periodic Social Assistance support, they had not acquired the pre-employment skills necessary to sustain employment. Some, like Grace or Sherry, could not tell time and so could not show up to a scheduled interview when asked. They could not tell when their breaks began or ended and were chronically late, a behaviour which did not endear them to their supervisors. They could not follow the conventions of dress that employers expect of prospective employees because they did not have the money to purchase the outfits which suggest competence, good taste, and professionalism. Their closets did not hold the "power suits" or simple little black dresses which are the staples of most working women. They tended to live in jogging pants, t-shirts, or jeans because that was what they could afford. "Dress-up" clothes for many of these women were the tight micro-mini's and thigh-high black leather boots worn by Julia Roberts in "Pretty Woman". They had all seen this movie, failing to see the patent falsehoods presented as truths. Julia Roberts was their role model, a hooker who had made it big; someone who used her body to make

her way in the world without having to spell or read. They did not see that this was a fantasy which kept them in their place better than any shackles.

These women could not demonstrate the academic competence to handle even the simplest entry-level positions, usually the only ones open to them. They could not spell well enough to take orders in a restaurant. They could not keep orders in sequence or concentrate well enough to work in cocktail lounges or bars. They were distractible and easily frustrated, especially when given too many things to do at once. They could not function independently or solve simple problems which arose on the job. Little things threw them off stride. They knew what to do if someone wanted coffee, but not if that person wanted their coffee with extra sugar. They could not make change, even with the new computerised tills which told them how much money to give back, because they did not know what each coin was worth. If these women were lucky, they found work as dishwashers or hotel housekeepers because these positions required little more than sheer strength, stamina, and the ability to stand for long periods. They usually laboured in the background, in positions of drudgery and relentless toil, until someone who could work faster and more neatly was hired, or until they injured themselves, and then they were gone.

Most of these women faced ongoing harassment from their supervisors or employers if they were lucky enough to find a job. They were sexually harassed or abused and were told they would have to perform sexual favours for their bosses or their bosses' friends in order to keep their jobs. If they quit,

their termination slips were improperly filled out and they could not claim Unemployment Insurance benefits. They did not understand how to launch an appeal if they thought they had been unfairly fired. They did not know to whom they could complain. They were rarely in unionised positions, where they might have an ally in their shop steward. They were truly alone and the most vulnerable of employees, dependent on the fragile goodwill of their employers.

If they could not manage to find other forms of work, the participants in this study often functioned as casual babysitters for other mothers in their neighbourhood. Any income was undeclared, to avoid problems with their social workers. The young mothers, like Janice and Sherry, did not tell their workers they were looking after children because they were themselves being investigated for parental incompetence. Often their only source of legal income, aside from Social Assistance, was from such unreported childcare. These mothers told me that they hardly ever smacked their young charges, except for such extraordinary situations as smearing faeces. They were very proud of their control and their parenting techniques. They did not recognize that the mistakes they had made with their own children were often replayed over and over again with the children of others.

The other source of income was from prostitution, the remaining avenue open to those with limited academic skills and no work experience. There was no timekeeping necessary in this position. These young women knew when to show up for "work" because the sun was going down. They

didn't have to punch a time clock or remember how long their coffee breaks were. On the street, each woman was her own boss; it was self-employment in the truest sense of the word. She worked for herself, unless she had a pimp, and then she worked for him, or for her. Many of the young women I saw had had female pimps, who were just as dangerous and as violent as the male pimps. They knew just where to hit so that it really hurt but so that it wouldn't stop their "girls" from continuing to bring in the money.

These women's stories were again supported by information supplied by the City of Edmonton's Community and Family Services department. They were poor because they were unemployed and they were unemployed because they were poor. They could not afford to work; employment meant that they would be cut off from the benefits which living on Social Assistance could bring. As working women, they alone would pay for their children's dental appointments, eyeglasses, doctor's visits, or prescription medications. They might lose their subsidy payments for childcare, leaving them to shoulder the burden of paying others to care for their children so that they could work. The little money they could get as low income wage earners would be less than they could make on government income support programs, and so they stayed home. They could not afford to work.

Research conducted by Streissguth, Aase, Clarren, Randels, LaDue, and Smith (1991) also documented the difficulties that individuals with FAS and FAE had when confronted with the simple demands of supported employment programs designed for individuals with lower cognitive

functioning. Because of their severe behavioural difficulties, individuals with FAS or FAE did not benefit from even the most basic of employment training strategies and were often classified as recalcitrant, uncooperative, or ungrateful. And for those who appeared to reject what little help was available, there were few other options.

Prostitution

Working the street as a prostitute, a FAS or FAE-affected woman was not significantly different from others who shared her lifestyle, the way she was in other settings. Problems with attention, concentration, and distractibility did not matter. Learning disabilities did not matter. Mental handicap did not matter. The clients of a street prostitute did not seek her out to have meaningful conversations. She did not need to make sense or remember the details which continued to escape her. The skills for which she was paid were more basic.

For these vulnerable women with few skills, prostitution became a viable option. It was something which required no training and there were always plenty of other, more experienced women who would gladly show a newcomer the ropes, especially if she could then take a portion of the earnings as rent for sharing her "patch" or section of the street. Pimps were always cruising too, trying to recruit new talent whose drug habits were less expensive and who were more easily manipulated. One of the best places in the city to find fresh faces was the local emergency shelter for youth. A few

nights in this environment was often all it took for a frightened young woman to do anything not to have to return. Young runaways could be easily seduced with the offer of steady food, a place to sleep, and a new outfit or two.

Prostitution was also easy to fall into if, like most of these young women, one came from a background where sexual abuse was the norm, rather than the exception. If a young woman had been in circumstances where she had been a sexual pawn and where her feelings were irrelevant, then prostitution introduced an element of control into her sexual behaviour. She could tell herself that she could choose who she slept with, although the reality was that she would usually sleep with anyone, provided they paid her. Even having money change hands in exchange for sexual favours was empowering for these young women. As one of my clients told me, "If you've been giving it away for years, then getting paid for it is a bonus."

With the exception of Sharon and Grace, each participant in the research had worked as a prostitute. Some, like Candy and Wanda, had worked the streets regularly and others, like Sherry and Janice, sporadically, whenever they were between relationships, short of cash, or heavily involved in drugs. Drugs were easy to get when they were on the street. Everyone used and shared what they had; it is part of the camaraderie which makes leaving this lifestyle so difficult. Drug habits and the attendant paraphernalia, clothes, childcare, shoes, coats, hotel rooms, and alcohol were all things to be shared amongst one's friends on the street. For these young women,who

had been unable to gather friends around themselves in other settings, the unequivocal acceptance of a street lifestyle became very seductive. It was easy to revel in any sort of friendship, even when it came at great personal cost, if they had never had it before.

Some of these young women began prostituting themselves at a very young age. Wanda was recruited by two older adolescents at the age of twelve. She admitted to working steadily for at least two years, until she was caught and charged with soliciting. Because she was underage, she spent a short time in a juvenile detention facility but was sent home after one weekend. Candy began prostituting herself at the age of ten, to look after her "boyfriend". She, too, worked steadily for approximately two years but now worked on a casual basis, whenever someone talked her into it or when she needed money for drugs.

The young women who had worked the streets had nothing but contempt for their clients; the "johns" who drove in from the affluent suburbs to use their services while waiting for the kids to finish their music lessons or who stopped for a quick session before heading home after work. The worst ones were the "suits", the high-pressure business men, lawyers, and accountants who often threatened to beat them or not pay for services rendered. The women preferred to service the working guys who understood how hard it was to make a living and who knew the value of a dollar.

The women also talked contemptuously about the "johns" who wanted

them to have unprotected sex. Although most of them knew this was dangerous, the extra money paid for sex without a condom was usually enough for them to disregard common safety practices. If I asked them directly about unprotected sex, each woman told me that this was something she had never done, but I found this difficult to believe. I knew how important money was, and how an extra twenty or twenty-five dollars might easily induce a vulnerable juvenile prostitute to change her mind. I worried about these women's health status and the constant risks they took, especially with regard to sexually transmitted diseases and other more deadly diseases like hepatitis or AIDS.

Alcohol and Substance Use

Apart from Sharon, who still lived in a supportive, vigilant family setting, each of these women reported a history of serious alcohol and substance abuse. They talked about the onset of their drinking and drug use, often at an age when many other girls were still playing with Barbie dolls or skipping on the sidewalk. Candy began to use drugs at age ten. Wanda began at age twelve. Sherry was not sure when she had begun to use drugs, but it was likely around age fourteen, when she was returned to Canada. Janice also began using substances and alcohol as a young adolescent.

These women told of using marijuana, hashish, hashish oil, cocaine, crack cocaine, heroin, chemicals like methamphetamines, LSD, and PCP or angel dust, and prescription drugs like Tylenol with codeine, heart

medications, "T's and R's" (a mixture of Talwin and Ritalin called "poor man's heroin"), diet pills, antidepressants, and antipsychotics. In short, they took anything that would alter their mood. They smoked, inhaled, and injected. They did not care about the dangers of substance use. Their lives were already so dangerous that using someone else's' dirty "rig" or syringe to inject heroin, didn't even register as important. They didn't care. They couldn't afford to.

For many of these young women, their drug use was precipitated by their involvement in juvenile prostitution. When they began to work the streets, they began to use drugs. Substances numbed some of the pain of selling themselves for sex. It was easier to forget that no one really cared they were working a street corner, if they were stoned. They could work in sub-zero weather, if they were so impaired that they did not feel the cold. They could work when they had not eaten for days, if they did not know they were hungry. The more they worked, the more they used and the more they used, the more they needed to work. They had no other way to support their habits. Shoplifting, break and enter, and property crimes could not give them the ready cash to purchase drugs. Prostitution gave them the money and the motive to continue to use drugs.

Alcohol use often began before the drug use. It was easy for an underage drinker to stand around outside liquor stores and persuade inebriated adults to buy alcohol for her. Liquor was readily available at home and rarely monitored. Although drugs were also available in many homes,

the parental "stash" was more closely scrutinised. It was easier to top up a half-empty bottle with water than to fill an almost-empty nickel bag of marijuana with something that would fool another user. Drugs were common, but inaccessible. Liquor was both common and accessible.

Candy, Wanda, and Janice talked about when they started to drink and for all three, it was at home before they had finished their elementary schooling. They discussed their drinking habits, alcohol-fueled blackouts, alcohol poisoning, and delirium tremens or "DT's" with the seasoned awareness of hardened drinkers. They knew what it was like to be so drunk that they still weren't sober a day after they had quit drinking. They knew about vomiting blood after a weekend binge. They knew about waking up in a strange hotel room or apartment after a booze-filled weekend, naked, beside a man they had never seen before. They knew all about being so hung-over that they wanted to die and were more than half-afraid they might. Booze and drugs they knew. What they didn't know was how to stop, or even why they should.

Sexual Abuse

Sexual abuse was another thread which was woven through the lives of more than one young woman in this study. Candy, Wanda, Sherry, and Janice all recounted stories where they had each been unwilling participants in childhood sexual abuse. The perpetrators were family friends, relatives, neighbours, parents, step-parents, foster parents or foster siblings, and the

boyfriends of their mothers, but they were never strangers. As children, these women always knew their abusers. They had more to fear from those they knew than from those they did not. A stranger could not hurt or abuse them more greatly than someone whom they should have been able to trust.

For Candy, Sherry, Janice, and Wanda, the abuse occurred within their own homes. The place in which a child usually feels most safe was the place where they were betrayed. The perpetrators were all invited into the family home by their caregivers, thereby giving them no access to assistance from those who are traditionally the first line of defence for a child. They were denied a place of safety and an audience with a caring adult who could look out for their needs. As soon as they grew old enough, they ran to the streets. For these young women, the streets, which are considered the most unsafe place for a child, were the places they felt most protected. The unspoken rules of the street ensured that they had others who would watch out for their welfare. There was a sense of "family" and safety in that setting that these children had not known before.

Sharon and Grace, the exceptions in this as in so many other aspects, were not sexually abused as children. They lived in secure, supportive homes with family members who were able to act in their best interests. Their parents were able to parent. Whatever the stresses these families faced, they did not interfere with their ability to provide appropriate care for their children. Grace did not have to flee her home because she was abused. Sharon expressed her desire to leave home, but for reasons of personal

independence, not for concern for her safety. They were different.

Health Issues

These young women were not the most sophisticated of medical consumers. They generally neglected their health and had learned at an early age not to listen to their bodies, especially when they were in pain. For many of them, pain, no matter the cause, was a trigger to dissociate - to unconsciously "forget" or block unpleasantness as a coping strategy - stemming from years of sexual and physical abuse. They did not pay attention to twinges or aches and pains, neglecting the most basic signs that there was something wrong with their physical state. They had learned to turn off the early warning signs to protect themselves from trauma but the result was often chronic poor health and untreated medical conditions.

These women often had chronic back pain arising from scoliosis, common in FAS and FAE-affected individuals. They had difficulty lifting heavy items, and standing or sitting for long periods of time. They could not manage the worksite demands of manual labour positions, usually the only ones for which they were qualified, and often ended up with back injuries and a worsened pain condition. Chronic respiratory infections, such as bronchitis, asthma, and pneumonia, stemming from the complications of premature birth, a difficult delivery, and underdeveloped lungs were also common and usually exacerbated by smoking cigarettes or taking other drugs. Ear infections, cardiac complications, gastrointestinal disorders and ulcers, joint pain,

broken bones, and head injuries were all common, some arising from longstanding, untreated health conditions, some as a result of the FAS or FAE condition, and some from the high-risk lifestyles these young women led.

Most of these young women, and not only the ones who were prostitutes, suffered from recurrent sexually transmitted diseases. On the rare occasions they sought medical attention, it was usually for antibiotics to treat syphilis, gonorrhoea, chlamydia, or other sexually transmitted diseases. Vaginal warts were also common. Precancerous cervical cells routinely appeared on pap smears although these young women usually did not ensure they got the necessary medical care to prevent cervical cancer. Janice, for one, had mentioned this to me. She would likely need a complete hysterectomy at the age of 20. With luck, this would stop the spread of the cancer, but it might not, and she would then be faced with another crisis she could not manage.

Because these young women neglected themselves, they rarely had personal physicians who were conversant with their health needs. Intervention for any medical problem was therefore complicated by their isolation from medical caregivers. They tended to rely on emergency departments to treat problems that arose, rather than cultivate a relationship with a local doctor. Whether they had a headache or a broken bone, their typical response was to go to a hospital, rather than a medicentre or general physician's office. They did not understand that they could treat symptoms before they worsened. They tended to passively wait until the situation felt

unbearable and then call an ambulance or a cab to take them in for treatment.

The young mothers in this study tended to use the same philosophy when caring for their children. A child's cold was not treated until it had become pneumonia. Infant ear infections lingered until the child's speech was delayed or until he or she was unable to hear. Fevers were ignored. Cuts, burns or scrapes went untreated. Immunisations might or might not be administered, depending on the child's age although school-aged children usually were immunised because they were in contact with public health nurses through the school system. Infants and toddlers often went unimmunised, unless a Child Welfare worker was involved with the family. Early screening for hearing or vision problems in children was a rarity, and if it occurred at all, was usually initiated by Child Welfare workers or the young women's social workers. This neglect for the basics of childhood health did not occur because these young women did not love their children. Instead, it seemed to stem more from their inability to attend to their children's needs. These women's own needs came first. If these were met, then they might recognize their children could also benefit from attention. But, if they were struggling with unresolved issues of their own, their children went without. These women were rarely malicious or deliberate in their neglect. Neglect was never planned, it just happened in the day-to-day confusion of their lives.

Pregnancy

With the exception of Candy, each of the participants in this research

had been repeatedly pregnant, despite the best efforts of social workers, teachers, parents, and child care workers. Various birth control methods had been taught to these young women, to no avail. Each continued her relentless drive toward parenthood. Some of these pregnancies were undoubtedly "accidents" where the young women did not intend to become pregnant. Because of their poor decision making skills and inability to form cause and effect relationships, however, the end result of many of their casual sexual contacts was pregnancy. They forgot their birth control medication or failed to accurately follow the directions. Other pregnancies were deliberate, as in the case of Sherry who needed the concrete proof of a child to ensure her partner "felt like a man". Janice, despite two abortions, had carried two other pregnancies to term because she thought she was in love with each of her daughter's fathers. Sharon became pregnant because she thought she loved her boyfriend. Wanda had become pregnant at age fourteen because she, too, thought she loved her various partners even though she did not know their last names.

Because most of these young women had serious, unresolved drug and alcohol habits, they did not stop using drugs or drinking during their pregnancies. Janice, Wanda, and Sherry had drunk heavily during each of their pregnancies. Janice was the most articulate about her drinking behaviours and revealed that, even though she was into the second trimester of her pregnancy, she continued to drink heavily, mostly beer and "coolers", light alcoholic drinks with a fruit base. She stated, "a course I'm going to have a couple of drinks". She said, "I'm not hurting a soul" and she likely believed

that. She could not contemplate that the child she carried was being affected the way she had been. Even when it was explained to her, she could not make the connection between the problems which stemmed from maternal alcohol consumption and her own drinking while pregnant. She would not stop because she did not think her drinking had consequences for anyone but herself. She, like the others, found it all too easy to perpetuate her personal tragedy in her own offspring.

The painful problems which had plagued many of these young women were being replayed in their young children. Janice's two daughters were on waiting lists to be assessed for significant attentional disorders and communication delays. Her oldest child had a severe articulation disorder and no one, not even her own mother, could really understand what she said. Her youngest was in a early intervention group for young children with special needs. Wanda's youngest child had been diagnosed with Failure to Thrive, a medical condition where an infant fails to gain weight and grow at an appropriate rate, and it was also suspected he would be developmentally delayed and mentally handicapped. Her oldest child had serious language delays and an attention deficit disorder. Sherry's child was born prematurely, and was developmentally delayed and seriously underweight, despite his placement in a therapeutic group home immediately after discharge from the hospital. It was too early to speculate about his language or attentional skills but the professionals involved in his care were worried. These children had been handed the torch of impairment from their disabled parents.

Therapeutic abortions were common among the women in this study and it appeared that termination was used as a form of birth control. If conventional methods had failed, or if the participant changed her mind about a relationship, she terminated the resulting pregnancy. Janice, Wanda, and Sharon had each had more than one abortion. This was not a matter of concern for them and they saw no reason to change their birth control methods. They viewed pregnancy as a natural consequence of sexual intercourse. If they did not want to get pregnant, they wouldn't have sex but if they were going to have sex, then they would get pregnant. It was no big deal. It was the way things went. Sex was a game of "Russian Roulette" they were willing to pay because it meant that, for a tiny space, they were not alone.

Permanent sterilisation was unavailable to these young women because of their age and because it was no longer a socially accepted way of controlling pregnancies in marginalized populations. Janice told of asking one gynaecologist if she could have her tubes tied; she was tired of being pregnant. She remembered that he laughed and told her she was still young and didn't know what she wanted. She did know, however, but still managed to become pregnant twice more before finding a more sympathetic medical practitioner who agreed to perform a tubal ligation. Sharon's family wanted her to have a tubal ligation but it was unavailable as an option. In asking for this, they had incurred medical censure and were forced to find a more supportive personal physician, after dealing with their previous practitioner for seventeen years. The other young women were not willing to give up their

fertility. It was one way of looking just like everyone else when other avenues for inclusion were denied. One pregnant young woman looks like another and no one stops to ask if a young mother has the necessary skills to parent, until it is too late.

Pregnancy gave these young women an opportunity to dream of a time when they would be looked up to and respected; something else which had been denied them. They each voiced their beliefs that their as-yet unborn children would love them without question and without reservation. They were convinced that they could fulfil their yearnings for unconditional love by becoming mothers, never realising that they did not have unconditional love for their own parents. Even the young mothers with children, who should have known that this was a fallacy, held onto the hope that, with the next child, it would be different. The next child would be the one who would answer their unarticulated need for love and acceptance. The promise of another child might somehow make them complete and close up all the empty spaces that they could not fill alone. These young women cradled their dreams of intimacy and of unconditional love as they cradled their unborn children.

Streissguth (1993) reported that repeated pregnancies were common in FAS and FAE-affected women. Perhaps this pattern was related to these young women's documented failure to consider the consequences of actions. Perhaps it lay in their desperate search for ways to belong or their need to be loved. Whatever the reason, it usually led to increased demands for age-

appropriate adaptive living skills which they, like the five women in this study, could not meet.

Suicide

Apart from Sharon, each of the young women who participated in the study had a history of recurrent suicidal thoughts, gestures, or attempts. Grace had attempted to overdose on antidepressant medication. Sherry struggled with suicidal ideation although she had not consciously acted upon any of her thoughts. Janice had tried to kill herself by overdosing on Tylenol two weeks before our first appointment. Candy had a lengthy history of self-mutilation, slashing herself with bits of broken glass or plastic, cutting herself with razor blades, or burning herself with cigarettes. Wanda had attempted to drink herself to death or overdose on street drugs more than once.

These young women saw suicide as a viable option. For them, it was the only way to stop the pain. They did not trust social workers, psychiatrists, psychologists, or other health professionals. These people had failed to hear them in the past and the participants had no faith they would pay attention if they asked again. The women relied on their own methods to work out their difficulties. Self-mutilation, not-quite-deliberate overdosing, and risk-taking behaviours all served to defuse the daily tension and give them the strength to continue on for another day or week or month.

Because these women had no ongoing contact with local health

practitioners, there was usually no treatment for the mental health disorders which contributed to their suicidal behaviour. Physicians who did not know a patient's history were reluctant to prescribe medications because of the possibility of drug abuse. The doctors who worked in the areas where these young women lived were all too familiar with the "sob stories" that patients concocted to get another prescription that they could then sell or abuse. Again, primary treatment fell to local emergency departments after the young woman had tried to slash her wrists, walk in front of a bus, or jump off a bridge. Ambulance attendants would take her to a hospital where she would be held overnight until she appeared stable. She might have her stomach pumped, if she had tried to overdose. Follow-up appointments for a psychiatric consult would be made, but never kept. A revolving door scenario often resulted, where these women would appear over and over again after making dramatic suicidal gestures, only to be discharged the next day. The underlying issues were never addressed because these young women were incapable of keeping their appointments or even of finding their way to an unfamiliar office.

These women tended to rely on the community resources designed for short-term immediate intervention, like telephone crisis lines. They did not feel comfortable with support group formats or even with most individual therapeutic approaches, since these placed an emphasis on communicative competency. These young women did not arrive at the great personal insights or revelations in awareness which are stressed in personal counselling. They needed a more directive, supportive, structured

therapeutic process which was difficult to find within the bounds of conventional intervention strategies. They did not feel allegiance to an intervention process which, once again, emphasized their weaknesses. They could not articulate what they needed to make progress and so they did not seek out the typical, long-term interventions which were available. They did not use the free or low-cost counselling offered by community agencies or government departments. They did not keep psychiatric appointments. They relied on a disembodied voice at the other end of a telephone line when their coping skills were at their lowest ebb. They felt safer in talking to a stranger than they would have in talking to someone with whom they had cultivated a relationship. Strangers were safer and less demanding than friends.

Streissguth, Barr, Kogan, and Bookstein (1996) also noted that suicide threats and attempts were common in individuals with FAS and FAE, especially between the ages of 12 to 20 and 21 to 51. More than half the individuals interviewed in their study had made suicide threats, and more than one quarter had made suicide attempts.

Emotional Functioning

Anxiety was a constant companion for all of these young women. They worried about the little details in their lives; where they would live if they were evicted from yet another apartment or how they would feed their children or themselves if they could not get to the Food Bank. They also worried about the bigger issues over which they had no control, such as neighbourhood

safety and their powerlessness. They had precious little time for anything but the necessities of survival, but what little they had, they devoted to anxiety.

Some of the young women, like Janice and Wanda, had specific phobias which interfered with their ability to function. Both were afraid to be alone but also did not want to leave the perceived safety of their apartments. Their agoraphobia prevented them from accessing services or caring for their children because they feared that bad things would happen if they left their homes. These phobias made them seem uncooperative, reluctant to seek help, and noncompliant because they were reluctant to acknowledge their fears. Other helping professionals, trying to get these young women into job training programs, academic upgrading, or supportive groups saw them as difficult and unmotivated. They did not know of the underlying fears which kept these women huddled in their apartments, unable to access the help offered to them. I was often told by the young women in this study that I was the only person to whom they had disclosed their feelings, because they thought others would think they were crazy and they were afraid of that as well.

Other participants in this study had more generalized anxiety, like Candy's fears about keeping up with her schoolwork, peer relationships, her family, and talking to others. She was also frightened of gaining weight which had led to the development of the bulemic symptoms of induced vomiting and deliberate starvation. Sharon was afraid of dying and Sherry was afraid of everything. Each of these women shared a pervasive worry that there was

something really, really wrong with them. They talked about their fears of being labelled "mental" or "retarded" and their reluctance to admit to any kind of emotional distress because of this fear. They worried that they could not perform appropriately and that others would recognize their inadequacies and limitations. Going to a convenience store was anxiety-inducing, in case anyone noticed that they were on Social Assistance benefits or could not count out change. They worried that a sales clerk or cashier might ask them a question that they couldn't answer. They were afraid that someone might notice they could not read well enough to find the items for which they were looking. Anxiety coloured every aspect of their lives.

Wanda and Candy reported symptoms consistent with panic attacks, including heart palpitations or an accelerated heart rate, trembling or shaking, shortness of breath or smothering sensations, nausea, dizziness, and derealization. When the symptoms became unbearable, they went to another hospital's Emergency Department, convinced they were having a heart attack or an acute asthma episode. They were prescribed medications to control the physical symptoms but the underlying anxiety disorder was usually never addressed, because they did not know enough to link their physical state to their emotional state. Overworked emergency department medical staff did not have the time to gain each woman's confidence; to worm out the truth behind the overt panic. They only had the time to treat the symptoms, leaving women like Sherry, Candy, and Wanda more and more convinced that there really was something dreadfully wrong with them; giving them another reason to be anxious.

Depression was also ever-present. These young women reported many of the vegetative symptoms of chronically depressed mood, including appetite and sleep disturbance, low energy, loss of interest in previously enjoyable activities, an inability to concentrate or make decisions, low self esteem, and feelings of hopelessness. Depression had been there for so long, most did not even recognize it as a problem. They thought that everyone felt like they did. Sharon, for example, stated, "I'm just getting fed up with the whole world". She felt that no one understood her, and pleaded, "let me live...I only want a little bit of freedom".

Wanda told me that she cried a lot. She often spent her days struggling to hold back tears even though she did not know why she wept. She could not control her moods and found that she had no energy to perform even the simplest household tasks, making her feel even more depressed. Janice told of her depression after her latest relationship broke up. She felt she had lost her focus and reason for living when her partner abandoned her and the children to care for another child from a previous relationship. Janice described her former partner as "...a god..." and when the relationship fell apart, she fell apart as well. Candy didn't want to talk about the unpleasant things which had happened to her because they made her cry. Although she did not specifically mention depression, others involved in her care saw her as a very sad young woman who did not have the insight or the coping skills to manage her depression. Sharon mourned the termination of her pregnancies and her inability to contemplate a more positive future but did not think she was depressed. Her family, however, felt that she was becoming

less positive and more introspective, unable to enjoy family activities that she had once gladly embraced. They worried about her mood and wondered about depression. Sherry wept when she admitted to her inability to function as a parent. She knew that there were many things she could not do for her young son, and she was deeply wounded by her inadequacies. She chose to incur the wrath of her social worker and therapeutic foster mother by running away rather than cope with the parental failure she was forced to confront each day in trying to care for her child .

Many of these young women talked about their inability to control their emotions. They told of being overwhelmed by feelings of anger, anxiety, depression, or restless agitation. Their emotions embarrassed them and made them feel different from others, who seemed capable of managing the little frustrations which would send them shrieking into a rage or a crying spell which they were powerless to stop. They were held hostage by their own emotional lability; prisoners of the wildly swinging moods which frightened them and made them seem dangerously unstable.

Many of the women talked about their inability to recognize different emotional states. Others around them would recognize that they might be angry, frightened, or frustrated but they could not. They did not have the vocabulary to label their feelings and any change in emotional state was something to be feared, since it triggered an immediate, explosive reaction. These reactions tended to be the same, no matter what the situation. Rage or tears were the only choices in their repertoire. Anxiety elicited the same

response as anger. Frustration wore the same face as fear. Janice said it best when she admitted "...all emotions feel the same...".

Some of the young women, especially those who had been heavy drug users, also talked about a sensation where things did not seem real. They often felt they were on the outskirts of events, somehow separated from reality by an invisible curtain which prevented them from feeling connected to the world. They talked about watching themselves go through the motions as if they were outside their own bodies. Sometimes they talked about themselves in the third person; "Candy says" or "Janice says". It was as if they did not understand they were talking about themselves.

Streissguth, Barr, Kogan, and Bookstein (1996) documented the mental health problems of their subjects with FAS and FAE. At all ages, these individuals had significant difficulties with mental health issues and most had been treated as outpatients by counsellors or psychotherapists, or had been placed in psychiatric or mental hospitals, sometimes for as long as one year. Identified mental health problems included attentional disorders, depression, suicide threats and attempts, panic attacks, and psychotic symptoms such as visual and auditory hallucinations. These matched the problems reported by the five women with whom I worked, with their fears, phobic behaviours and repeated, attention-seeking suicidal gestures. Depression and agitation were there, too, leading to a sense that the world was too complicated for them to manage, even if they were able to clear their heads of the racing thoughts which prevented them from making decisions or solving simple problems.

Lemoine and Lemoine (1992) also commented on the preponderance of mental health problems in the original population first identified as having FAS. They found that mental health problems were the most severe of all impairments in adults with FAS. Suicide and suicide attempts were documented, along with fearfulness, euphoria, excitement, anxiety, and depression.

Data from German researchers (Steinhausen & Spohr, 1994) also documented psychopathology in FAS-affected individuals over the age of 13. Conduct disorders, emotional disorders, hyperactivity, and social relationship problems were noted for both males and females.

Searching For Meaning

Many of these young women also had a strong belief in the supernatural. They talked calmly about the ghosts that lived in their apartments; the spirits which sometimes watched out for them, or sometimes just watched. They talked about the men they could not see who touched them under the blankets at night. They were convinced they were not alone, in spite of the loneliness of their daily lives. They had all known people - family members or other street kids that had died - and believed that they were still there, just invisible. They would not acknowledge that these people were gone. They had suffered too many losses and been isolated too long to let anyone, even after death, leave them.

These same young women also talked about how magic was going to somehow change their lives and make them competent, successful, and happy. They believed in luck and in positive thinking. They did not want to dwell on the negatives because talking about this engendered more negativity. They only wanted to have happy thoughts because happy thoughts meant that happy things would then take place. There was no sense of personal responsibility. They seemed unable to see that, in many situations, they made their own "luck". If good things happened to them, it was luck or spirits or ghosts. It had nothing to do with them. If bad things happened, then they had somehow incurred this by thinking the wrong thoughts or doing the wrong things. They underwent superstitious rituals to ensure that these negative events would not occur again. They burned candles or cut up pictures, or made little shrines in their living rooms.

Most of them did not subscribe to conventional organized religious denominations although some had grown up in traditionally religious families. Some had gone to church and Sunday School, had their first communion, and celebrated the rituals of the Christian church. The lessons they had learned in their Sunday School classes did not seem meaningful to them now, and they laughed about their naivete and youthful beliefs that God was somehow listening and caring for them. They were not going to make that mistake again because God had let terrible things happen to them. They didn't like God anymore, but they still held onto the notion that He, and it was always "He", was somehow out there, waiting to make bad things happen again. They believed in God the same way they believed in luck. Like luck,

He was there, but unattainable. He was not for them. Instead; they believed in their own rituals and sought, when they had time, to create their own meaning. They relied on snippets of information gleaned from talk shows or television programs on the occult, or things they had heard from others. They were solitary seekers, searching for the meaning that would somehow justify the pain of their existence.

Some of these young women were convinced that they had failed an important test somewhere, either in this or some past life, and their struggles were the consequence of their continual inability to master these necessary but unknown lessons. Their problems were their responsibility, and their impairment was their responsibility. They had not walked the right path and they were doomed to walk this present road until they found the critical junction and took another direction. For these women, there was no point in making changes, because they knew they were learning a lesson from this life that they would have to repeat again and again, if they failed to learn it this time. There was a stolid sense of fatalism that permeated their world view. Their resistance to change lay in a personal spirituality that would not permit any deviation from the status quo. They knew all too well the pain and despair they faced each day. The thought of facing it forever was too much to bear and so they doggedly soldiered on, making the same inappropriate choices, hoping that this time they would learn the lessons they had missed in the past; hoping that this would break the cycle.

Isolation

Each of these five young women lived in splendid isolation, confronting the same difficulties in the same manner, unaware that, around them, others were making the same decisions with the same tragic outcomes. They did not know that there were others who had the same problems, for the same reasons. At first, they did not believe me when I told them that there were others just like themselves. They thought I was just making this up, to make them feel better. They could not believe that other young women had the same problems because they only had the capacity to entertain their own difficulties. They had not developed that quality of empathy which encourages the awareness of a greater "other". They were not selfish, as that implies an initial awareness of others' needs and then a deliberate ignoring of those needs. These young women did not intentionally disregard others' needs because they could not understand that others had them. They could only entertain their own circumstances.

Sherry wept when I told her that I had met others like her, with the same problems, crying, "I thought I was the only one". She desperately wanted a community to whom she could belong. She talked about her fears that she would never be accepted but she could not see how to gain the acceptance she craved. Sharon also wanted someone to understand her. She wanted to be a part of the wider community. She wanted to do things that her peers did, like joining clubs, going out, and having "...a little bit of freedom..". She described her life, saying, "...I feel like a dog on a chain. They keep trying to

yank me back...". Janice wanted acceptance and understanding but could not recall a time in her life when this had been available to her. She talked about her schooling and her lack of friends. As a child, she had turned inwards, preferring to draw alone rather than risk rejection by asking if she could play. Candy thought she had friends, but these were the other young women who kept the money she made when she worked the streets. Wanda did not talk about friends at all. Instead, she talked about her family even though they were singularly unsupportive.

These young women wanted friends who would accept them as they were, without demanding skills or behaviours they could not consistently produce. They were tired of being alone, or of having to meet impossible standards before others deemed them worthy. They did not know what else they needed to do because they thought they had done the best they could. Sherry, Sharon, Janice, Candy, Wanda, and Grace only wanted to be judged worthy enough of friendship.

Despite their desperate longing for companionship, they shunned contact with others. Group situations made them anxious. They could not keep up with the flow of conversation. People talked too fast or used too many big words and they were always playing "catch up" because conversation shifted more rapidly than they could grasp. By the time they had formulated their responses, the topic had moved to something else and they were left behind, as they were in so many other ways.

These young woman were unable to cope with the demands of individual contact. They were too intense, too demanding, too needy. They wanted a friend because they needed companionship, not because they believed they had something worthwhile to contribute to another individual. A friend was someone for them and and there was no reciprocity in their understanding of companionship. A friend was there to meet their needs and to make them feel less lonely. They had no concept of the implicit sense of sharing that makes friendship all the more valuable. They could not contemplate the possibility that they had anything to offer, instead focussing on what others could offer them. Theirs was a greedy sort of friendship, rooted in intense loneliness and a desperate grasping at connection.

Contact also had other pitfalls for these young women. They were expected to make sense; to behave in conventional ways. Conventionality, however, was not a familiar concept. It implies the ability to understand a given situation and then follow the unspoken rules which govern one's language, actions, and dress. Conventionality is complicated and these women were more suited to simplicity. When confronted by choices, they could never decide what was appropriate. They were forever guessing, and usually arriving at the wrong conclusions. They were unpredictable and impulsive. They said, and did, and wore the wrong things. They did not recognize when they had erred. They never apologised because they did not know what they had done wrong. They were an embarrassment. Others apologised for them, grew tired of this, and then abandoned them.

These young participants knew they were somehow different from most of the other people they knew. They did not know how to communicate their differences and so they remained isolated when they really longed for intimacy. They did not have even the most basic of skills necessary to sustain long-term relationships and this craving was never satisfied. Despite their desperate longing for a sense of community, closeness bred pain and humiliation for these young women. Strangers were the ones who made no demands and did not expect what they could not give. They wanted what they could not have - the intimacy of a friend with the distance of a stranger.

Inequality

Grace, Wanda, Janice, Candy, Sherry, and Sharon were systematically excluded from the processes which others usually take for granted. They were never seen as equals within the school system. Instead they were identified as "special needs" students who required more than their fair share of support. School was where they were first fragmented into a cluster of problem behaviours or diagnostic criteria. School was where they were first assessed and found wanting; first made unwilling partners in an identification procedure which had begun the process of depersonalization. School was where they also first learned the power which comes from refusing to follow the myriad of orders, suggestions, and recommendations made in their best interests and in which they had had no part.

These young women took the lessons in inequality learned in school

and applied them to the commonplace societal activities of community involvement. Too transient to remain in one place long enough to be placed on a voter's list, register in a community league, feel comfortable as a parent in their children's school, or develop a familarity with shopkeepers, they drifted like ghosts through the neighbourhoods which catered to the disconnected. They haunted the same run-down apartments, cheap inner-city rooming houses, pawnshops, and bars which their mothers had frequented. In those settings, money equalled power and they were bereft of both.

In employment situations, they also had no equality. They had none of the skills which they might have used in exchange for workplace security. They could not barter their competency for fair wages or supportive employers. Sherry, Wanda, Janice, and Sharon could not compete with others for even the most basic of entry-level positions in competitive employment. Last hired and first fired, they came to expect the inequities which flowed from their inability to understand and execute workplace' demands. Expectations of inequality also governed the experiences of the young women who had worked as prostitutes. Apart from the dubious protection offered by their pimps, they had no say in what happened to them. They were outsiders, treated as less than human by their customers and by those who lived off their earnings. Used to being depersonalized, they became adept at dissociating themselves from the physical and emotional hazards of their occupation. After a few years of prostitution, these young women were even more convinced of their intrinsic worthlessness and saw

inequality as their due.

These women experienced no equality in their dealings with governmental agencies. They were forced into pre-employment or job readiness programs by well-meaning employment assistance workers who had no time to hear the stories of abuse, powerlessness, and despair which had prevented them from finding and sustaining employment on their own. They were forced to open their doors to parent support workers, child care workers, social workers, psychologists, and psychiatrists who documented and evaluated every detail of their lives. They were forced to accept help from professionals who did not have the time to explain their involvement. They were forced into assessments by agencies who wanted to determine their competencies as students, employees, parents, and persons. Even as adults they were still seen as problems, first and as people, second. And like they had done as school children, they practiced the fine art of refusal or passive waiting until professional patience wore out. They would not cooperate with any process which reinforced the inequality they had experienced since childhood.

CHAPTER SEVEN

Celebrating the Differences

Although the similarities contained in each story was painful and compelling, there were still subtle differences which made each recounting somehow different. For Candy, Wanda, Janice, and Sherry, these differences were tiny variations in personal action leading to a sad sameness of outcome. Each of these young women had arrived at the same place by following ever so subtly individuated paths. For Sharon and for Grace, the woman whose story had first moved me to reach past my seemingly complete knowing to a new understanding, the differences were more profound and deserving of reflection. There was a "something", or perhaps a collection of "somethings" which somehow separated these two from the others, no matter what the surface similarities which had, at first, shrouded the differences. This was no easy task, waiting for the obscuring samenesses to slowly dissipate, but yet so necessary. In the waiting I once again found a deeper understanding; the backward arc of the hermeneutic circle where the uncoverings led to a new understanding so different from what I first had thought, deserving of its own reflection.

Sharon's Story

As I read over the previous themes, I was struck by an interesting anomaly. Again and again, I had prefaced my comments with the phrases

"...apart from Sharon", or "except for Sharon" , or "with the exception of Sharon". What was the difference between this young woman and the others? What had made her immune from some, but not all, of the conflicts that Candy, Wanda, Janice, and Sherry had suffered? She clearly shared the features and behaviours of these other young women but had not shared the consequences. She was the one exception to the rule of dysfunction uncovered in the lives of the others.

This difference did not lie in intellectual functioning or stronger adaptive behaviour skills. Sharon's capabilities across a number of areas were commensurate with the other young women. She did not display more strengths. Her weaknesses were the same as the others in that she could not perform at an age-appropriate level in any academic subject area. Her language skills were extremely weak, as were the linguistic capabilities of the others. She could not manage stress or express her emotions any more eloquently than her peers in this study. She was as restless, inattentive, distractible, and unfocussed as the others. She was just as socially isolated and frightened. In so many ways, she was typical, but her story was not. It did not share the relentless, ongoing sense of tragedy present in the stories of the other young women. There was still a feeling of optimism and a belief in the future. Sharon may have been naive but she had not given up her dreams. She was still able to contemplate a place for herself within the wider world. She had a sense of hope which allowed her to contemplate alternatives, and even though they were unrealistic, she could still believe that things might be different for her.

Sharon, apart from the chaotic first 6 months of her life, had lived in the same small community, surrounded by the familiar faces of her parents and siblings. There was a permanency to her family that most of the other women in this study did not know. Unlike these other women, the man she called "father" had not changed from month to month, or year to year. She had not been placed into foster care like the others whenever her mother's problematic lifestyle and drinking spiraled out of control. She had not quickly acquired and then just as quickly lost brothers and sisters who drifted in and out of her life whenever her mother changed boyfriends. Her family was a constant; never wavering or deserting her. While she railed against the sameness of things, she was nevertheless protected by the consistancy against which she chafed. Although she would not understand this, the other young women I knew might have considered themselves privileged to be as bored as Sharon claimed to be. They, too used to coping with complete disarray, would have welcomed boredom and some might even have been capable of labelling it "stability".

Sharon was the only one who still lived in a stable, supportive family. She had a clear notion of where she fit within that narrow sphere and she had been protected and nurtured, as the others had not. She knew that her family was there to look out for her, no matter what problems she encountered. She knew that she was loved and this knowledge gave her an invisible cloak of protection, like the magical garments bestowed on fairytale heroes. She could pass through the perils unscathed because she was supported. Her family had fought battles for her. She knew she had not

been abandoned.

Sharon also knew where she fit within her small town setting. Everyone knew her and her family and, if they did not know of the circumstances surrounding her birth, they were nevertheless aware that she was rooted within the wider community. She had a place, although she longed to leave it, and would always have somewhere she could call home. The other young women in this study did not have this luxury of connection to a sense of place. They drifted from one apartment block, neighbourhood, or town to another, never staying long enough to find a reason to remain. Unlike these other women, Sharon always knew where home was. Her bedroom always looked the same. Her clothes hung in the same closet or lay in the same dresser drawers. The same key still fit the same front door.

Sharon wanted to leave home and although there were many things for which she was not prepared, she had the luxury of making her own decisions on this matter. Although her family worried about her ability to look after herself, her right to independence was not questioned. Her family was not concerned with whether or not she should go, but rather how and when she should leave. They knew that inevitably Sharon would move on and their anxiety stemmed from their lack of knowledge about the support systems which would allow their daughter to function as independently as she could. They knew they could not hold her forever, and they did not want to. In their eyes, Sharon had as much right as any of their children to live as an adult, responsible to herself. While she needed more support to reach this goal, it

was never denied her. What her family wanted was the time and the assistance to plan for her leaving, not more ties to keep her at home.

The other young women I worked with had never had this type of support. They made their decisions alone, without assistance from anyone. There was no recognition that they were ready to leave childhood behind and enter the more complicated world of adulthood because each had never really been a child. They had never known what it was like to be cared for and supported. They had never felt the security of structure and consistency. These young women had never been free of the responsibility of looking out for themselves. They had raised themselves, for good or for ill, and they alone were responsible for their decisions. They made their own choices and suffered the consequences. There had never been anyone to cheer them on. No one was there to coach them or to determine when they were ready for more responsibility. They had always had all the responsibilities.

Each of these young women had been thrust into the wider world before it was time. Whether they left of their own volition or they were forced to leave, they knew they could not stay. They escaped from beatings at the hands of their parents or step-parents, their siblings, or the drifters who found their homes a handy place to "flop" for a day, a week, or a month. They fled sexual abuse. They left parental alcoholism and drug abuse. They ran from continual threats, criticism, and soul-destroying belittlement. They ran from jealous mothers who couldn't bear that this week's boyfriend was more attracted to the child than to them. They were abandoned when their families

moved during the school day without telling them. They would go to class at 8 o'clock and return to an empty house at 3:30, with no forwarding address left for them to find their way home again.

Being discarded like an old shoe was not an unfamilar experience for the young women who had remained at home until age sixteen. While they were under sixteen, their families could receive extra money from Social Services and the Family Allowance program. Over the age of sixteen, however, they became a burden. They were no longer sources of income and, in a simple debit-credit system, they had become debits by virtue of their age. Once they were too old to bring in extra income, the problematic behaviours which had been tolerated in an attempt to support the family suddenly became intolerable. It was too easy for their caregivers to wash their hands of them and pronounce their attempts at parenting as failures. There was no incentive to continue the struggle with a child who was no longer contributing and so each was inevitably pushed out.

Wanda, Candy, and Janice were also liabilities in other ways. They tended to indiscrimately disclose the sordid details of their home lives, and, despite the beatings and threats, had not always learned the sacrostanctity of family secrets. Because of their ingenuousness, teachers or social workers came to know too much about the lives they lived as children. Family privacy was invaded and there were too many prying eyes for caregivers to continue their dysfunctional patterns of behaviour. It became much easier to turn a rather troublesome adolescent over to Child Welfare than to make the long-

term committment to change necessary to have her remain in the family home. She was literally more trouble than she was worth.

Each of these young women was used to being sacrificed on the altar of another's needs. Unlike Sharon, whose wellbeing had been paramount to her family, Candy, Wanda, and Janice's needs were always at the bottom of their family's priority lists. They were too used to waiting to have their requests met or their questions answered. Sharon, who had never waited for anything, was unable to grasp the fact that she came first. With her faulty sense of time, it seemed like years for her family to fulfill the demands she made of them. For the others who had shared their stories with me, there was no sense in asking their families for anything. They had given up long ago.

Grace's Story

Grace, whose story also differed in some aspects from the tragedies revealed so starkly in the lives of the others, had also shared the twin blessings of stability and acceptance which Sharon knew. Like Sharon, she had lived in a supportive, loving adoptive home. She, too, was a wanted and cherished child. Her parents had struggled to meet her needs, helping her with her schoolwork when she could not keep up with other children or trying to find work for her when she finally left school for the last time. Even after adolescence, when things fell apart for her, Grace knew that she had a place where she was accepted unconditionally. Despite the vast difference in lifestyles her parents had never abandoned her and had tried to their best to

keep in touch with Grace and her children. Although Grace lost custody fo her children after their apprehension and adoption her parents maintained contact, visiting their grandchildren and continuing the celebratory rituals of birthdays and Christmas. And when Grace could no longer maintain the dysfunctional, self-destructive lifestyle she had embraced as a young woman, her parents were there, waiting for her with no recriminations. She was their child, and they were her parents. Nothing else mattered. She could go home again.

Grace was lucky. She returned to her childhood home, with its familiar sense of sameness. Unlike Sharon, however, Grace found comfort in the simple repetition which had changed little with the passing of time. She did not chafe about the rules and structure; she was so accustomed to chaos that regulation was a welcome relief. She did not complain about helping her mother with household chores, or with going to the corner store to run an errand for her father. These were tasks that she could manage and her parents assumed responsibility for the more complex issues with which she now knew she could not cope. Grace settled into that familar, comfortable routine with relief and a sense of peace. She had discovered for herself what the world had to offer and she could now discern that much of what she had wanted had not been for her.

For the other participants in this study, there had never been that sense of love, acceptance, and comfortable sameness which Sharon hated and which Grace had finally embraced. They had never had homes which had

protected them from the hurts of an unaccepting world. Home was where they learned their first lessons in pain, distrust, and fear. If they were ever to reach the same point as Grace, where they might want to change their dysfunctional lifestyles, there was nowhere for them to go. They could not return home because they had no homes. These young women had never had a solid starting point and so did not learn to value stability. They had never felt a part of their communities and came to trust being unconnected. They did not know acceptance and learned to walk alone. They did not feel safe and discovered that danger was acceptable, even desirable, because it meant that they were still alive.

Sherry, Candy, Janice, and Wanda never known what it was to be protected by competent parents capable of shouldering the responsibilities of raising children with special needs. Sharon and Grace had never known what it was to be abandoned. And perhaps this was the difference which separated Sharon and Grace from full membership in the sisterhood which had so completely embraced Sherry, Candy, Janice, and Wanda.

CHAPTER EIGHT

Exploring Beyond the Boundaries

I had not counted on this work to change me in any substantial way. I was comfortable with my skills and professional expertise. I thought I knew everything that was necessary to work effectively in a highly charged atmosphere. If I didn't know, then I was sure I could look it up. I had a well-practiced approach which protected me from the raw realities that my clients faced each day and I knew that, at the end of the day, I could go home to a comfortable existence. My world and the world of my clients did not overlap outside the office. We inhabited different universes. With these young FAS and FAE women, however, I found that this distinction was no longer accurate. The previously clear demarcations were becoming increasingly blurred and I was exploring uncertainties that I had once held to be truths.

I confronted problems that went far beyond my mandate for each particular case and forced me into an examination of my own understanding of "psychologist". I struggled to go from a simple service delivery model in which I assessed for a particular problem, towards a wider, inclusive process which addressed far more than the initial reason for referral. I found that I could not ignore other aspects of a woman's life when all the fragments, even the ones which seemed irrelevant, were necessary in the generation of possibilities.

Exploring Professionalism and Power

Before beginning my journey into the world of these young women, I had developed a personal style which suited me well. I allotted six to eight hours for each assessment; a standard to which other clinical psychologists I knew also adhered. In that time, I could conduct a comprehensive interview, covering all the background necessary to establish predictability. I could ensure that most of the assessment instruments would be administered, and even had some time left over to toss in a few extras, to ensure that I was getting accurate information. I had a comfortable routine that did not vary much between clients. To be fair, I was also seeing individuals whose personal lives were not as tormented or as convoluted as many of these young women, and I could easily meet my goals of ethical, competent practice within the hours I had allotted.

When the focus of my practice began to shift towards these marginalized young women, however, I soon found that this comfortable routine was no longer acceptable. I could not work within the six to eight-hour boundaries established in the previous years. I could not neatly gather up the necessary information in a one-hour interview. One hour was only enough time to break down the barriers and establish the fragile links that allowed each young woman to begin her story. One hour allowed us to get started, but not much more. It often took two to three hours to follow the tortuous path of each life story.

At first, I did not know how to change the perspective which I had held for so many years of practice. I was changing my understanding of who I was and what my professional role was to be, and that was a confusing and sometimes painful process. I had spent considerable time becoming comfortable with a way of being that was no longer comfortable. I felt rather adrift, uncertain of how I would change, but knowing that it was inevitable, even necessary, if I was to continue to do what I loved. I thought about all my ways of being the person I thought my role dictated. I explored my language, my dress, my behaviours, and my sense of professionalism. I thought about allegiances and loyalties and responsibilities. In short, I began to question things that I had once merely accepted as given.

In this exploration process, I wondered about how I had worked with other women in the past, especially those who had come to me unwillingly, fearing the worst. I questioned how to imbue these women with a sense of participation in a process which was set up to make them feel excluded. I thought about how I could make them feel valued, when all the odds were against this. And, again and again in my questioning came the idea of language, of the words we use to bid others welcome. At first, I only wondered about spoken communication and the words which convey so much meaning for me and for the others who, like me, love the shared richness of language. As I explored the concept of language, however, I came to also question the nonverbal messages which I sent to each of the women who came to my door.

I knew that many of these women were keenly visual; observers of the small details that for so many of us go unnoticed on a conscious level. They had learned too well what happened to those who could not see danger coming. While they had never learned to judge mood from spoken language, they were cued to the inherent danger contained in a narrowed pair of eyes, a raised fist, or a curled, snarling lip. These women knew how to watch for the tension which precedes physical aggression. They were skillfully adept at visual recognition and, even though they were often unable to articulate what they had seen, they knew very well the meaning behind a gesture or a stance.

They observed everything about their surroundings; where the doors were, how many steps to my office or to the washroom, where the coffee smells came from, the other clients or professionals who might be sharing their space, the way the receptionist moved about her office, and the people who passed up and down the hall outside. Some of them, used to escaping at a moment's notice, took special care to trace the path back from my office to the common area, just in case they needed to leave as they had done so many times before from other situations. I learned to respect this time of mental mapping. These women needed the surety of escape before they could willingly enter an unfamiliar place with a person they did not know.

These women carefully watched me in the same way they watched all the others who had told them they were there to help. Most made themselves as small and inobtrusive as possible when I approached them for the first

time. They sat self-contained and cautious in their chairs, observing the way I stood or made eye contact or carried myself. They watched to see if I made the effort to make physical contact with them; reaching out to shake hands or to show them, through gestures, how to find their way in unfamiliar surroundings. They watched how I greeted others in the office, to see if they were being treated differently.

They needed time to see me and to make a mental picture of who I was, as much as they needed a mental map of where they were. They could not trust a person they had not had time to observe since watching was safety. They could trust their eyes where they could not trust their ears. I learned to be in the office early and, if possible, to be in the common area when they came in. If I was busy in my office, I made sure I came out to introduce myself early and to chat briefly about little things, like the weather, how I had forgotten my shoes that morning, or how busy our office seemed to be. I learned that what I said was of less importance than my physical presence. Their eyes never left me, watching not what I said, but how I said it.

Once each woman had made her initial visual inspection, I left her alone for a few moments before asking her to come into my office. This seemed to help somehow. They did not appreciate being rushed into situations they did not understand and often did not like. They needed time to sit and relax, perhaps to leaf through a magazine or ask the receptionist where they could have a cigarette. Again, I learned to appreciate the waiting period where I could also gather myself for the task ahead, just as they were

doing and, at the end of this anticipatory stage, we were usually ready to begin the process of uncovering.

With each client, I prefaced my work with an explanation of who I was and what I thought my "job" was. I used plain, simple language and talked about my understanding of what I could and could not do. I set each assessment within a context of positive change and support, linking each appointment to a sense that things could be different, if the participant wanted that as a goal. I talked about the limitations of what I could do but also told each woman that I would do what I could to help her. I told her that, regardless of who had sent her to me, my responsibility was to her and I would do my best to help her find what she needed. I told her I wouldn't pretend that everything was fine, if I thought it wasn't, but I wouldn't give everything a negative cast if that also wasn't true. I asked each participant to be honest with me, because I would be honest in return. I presented my goals clearly and in language she could understand and gave her the time to think about what I said.

I explained the basic components of a clinical assessment, so that she would understand what would be happening and how she would spend her day. I did not want her to feel that she was so unimportant that she did not need to be informed. I talked about the interview process, describing it as a way to understand what was important to her. I explained that, in order to make suggestions which might be helpful, I needed to know what she had tried before. I had to know what had worked and what hadn't worked,

because I didn't want to waste her time. The notion that each participant's time was somehow valuable was another unexpected novelty, one which often elicited a strong nonverbal response. After a period of stillness where I could almost see each woman turning this over and over in her mind, she would move her chair closer to the desk, leaning in to share the details of her life with a new sense of understanding. I was providing her with a context and asking her as an equal, and she responded as one. She could see a reason for each increasingly personal question and, as a partner, was willing to tell me what I needed to know.

I also told each woman about the debriefing process, that essential component of a clinical assessment where information is shared, results are discussed, and recommendations are communicated. I wanted her there, to be a part of the decision-making team. I knew that was not a common practice for young women such as these, since each, despite previous assessments, had no knowledge of the results obtained from the earlier testing. They did not know that the information gathered was there to be shared and explained to them. Although these women were crucial to every stage of the assessment, they had somehow been deemed unnecessary in the most important segment, that part where decisions were made. They were made to feel extraneous in the planning of their own lives. It was no wonder that most of them felt little allegiance to earlier recommendations, apparently made in their best interests, but without consultation.

In addition to ensuring their presence in the debriefing, I also made

sure that the women with whom I worked knew they were privy to written information concerning the information gathered about them. Early in my career, I had been a part of case conferences where documents were circulated to everyone at the table, except for the client. Each sat with her hands in her lap while others flipped through the pages to read the intimate details of a life which seemed so unimportant that it was unworthy to share even with the one who had lived it. This blatant exclusion was no longer acceptable to me. I had reached a stage in my professional awareness when I could not be part of such depersonalization. It had become too uncomfortable and so I made sure that every referral agency knew I would prepare written documentation for the clients sent to me. That way, when the written material was passed around the table at the meetings over which I presided, there would be a copy for everyone. No one would be excluded from that act of communion.

These documents became talismans for the women who participated in this sharing of experiences. They could hold the pages in their hands, and while they could not read them, they knew they were about them and for them. It was proof that they had mattered enough to be included in the process of planning a future that could be different if they chose. Each document was their story, but couched in the language that others would heed. They could wave it in protection when meeting other professionals who might not have the time or the inclination to listen to their stumbling words. They had been part of a process where they came away with something tangible and this gave them a sense of power sometimes strong

enough to make things change.

As I explored my professionalism, the patterns which had previously governed my interactions with women such as these began to change as well. I did not behave in a manner to which these young women were accustomed and they did not know how to categorize me. I was neither a friend nor a stranger. I was not a counsellor, social worker, child care worker, parent aide, or teacher. Although I remained a psychologist, the differences in my approach were such that I had become someone these young women had not encountered before. I took the time to listen; to somehow work past the fears and establish a sense of trust. Perhaps I had been able to make the impossible happen. I had become the intimate stranger; the friend they did not have to see again which then freed them to take the next step towards contact. I was the "friend" they had dreamed of, who made no demands on them, who did not judge, and who was only there when they wanted. Although I had to set the first few appointments, subsequent contact was at their leisure. They could see me or not, as the mood struck them. Because my rituals were different, they sometimes felt safe enough to continue their tentative relationships with me.

Exploring Language

For these women, who struggled with linguistic competence as I was accustomed to defining it, a verbal accounting of their lives was difficult. Their memories did not follow a logical sequence and I often had to sit patiently,

waiting for the words to lay themselves out in some sort of confused order. When the words finally came, it was clear that these women did not use a conventional vocabulary. They had a rather limited selection of verbs, nouns, and adjectives, most of them ones which I would hesitate to use myself, but these were their words and I could not show any discomfort or censure, lest I turn off the flow which helped me know who each of them was.

As I became comfortable with the waiting, I began to explore other ways of making these women feel empowered. I chose to alter my style of eliciting information. Along with the more traditional direct questions, I also learned to interject with an empathic comment or a nonverbal response. I gradually came to realize that these were often the triggers for other, more painful memories which would not have been revealed if I had relied on a more direct question. This was where the time went; in stories which were tangential, rambling, and confused but essential to the process of understanding. These women did not care about time. They were more concerned with being heard than in wondering about the passage of another hour. This was a novelty, this process of being listened to, and they were in no hurry for it to end. They seemed to enjoy this unfamiliar equality and found it as difficult to stop talking as it had been to begin. Inside each of these women, who had first appeared so inarticulate and language-deprived, was a torrent of words that I did not expect. Their words and understandings were not mine, but no less valuable for the difference.

Another unexpected surprise lay in these young women's pleasure in

language, once they were sure of an attentive audience who would not pass judgement. They became engrossed in the novelty of using words, rather than their traditional larger-than-life gestures, as a means of explanation. They tried out new words or picked up vocabulary they heard me using, and threw it into their own sentences. They played with language, experimenting with words that felt good in their mouths. They also spoke with grace, describing their situations with a surprising beauty. Sharon likened her existence to a dog on a chain, always being pulled back from the brink of some discovery. Candy talked about her placement in secure treatment by making an analogy between the birds outside the office window and her captivity, "See those birds outside? They're free and I'm locked up." Janice described her lost childhood by saying, "I need to be Janice. Janice is a child that had been taken away from her." Sherry described the childhood hyperactivity which had set her apart from other girls her age, saying "I was an active little boy for a girl."

I occasionally used the language of artistic expression as well, giving these women the opportunity to convey their feelings through drawings. While Janice, Wanda, and Sherry were extremely reluctant to explore this medium and refused to participate, Candy and Sharon gladly embraced drawing as a less threatening way to share their emotions (See Appendix C). They could sketch things they could not say. I learned about these young women's self-image, their need for stability, and their aspirations without the words which only made each more self-conscious. With a pencil and a piece of paper, they were no longer the voiceless women who could not

communicate. Their linguistic deficits became immaterial; no longer a source of frustration or misunderstanding.

Exploring Detachment

With my developing awareness of the power of waiting and of words came another crisis of profession. I began to struggle with the idea of detachment, that clinical perspective which permits a practitioner to be with, yet be uninvolved with a client. Over the years, and through my training, I had learned to distance myself from what I heard because that was the way I understood that I could be most effective. I believed that involvement was over-involvement; unhealthy to me, to my clients, and to the goal of impartiality to which I ascribed. I had learned and continued to teach that detachment was necessary and that effective practice could not occur in its absence. Detachment was easy during the process of actual assessment, where one's focus was on accurate administration, the recording of responses, and the minutia of scoring. Detachment was, however, increasingly difficult to summon during the painful process of interviewing. There were times when I could not stop myself from becoming involved and I could not remain distanced from these women. I felt compelled to reach across that seemingly vast expanse of desktop, which had served to subtly remind me of my "separateness", to make contact.

Exploring Acceptance

I began to question even the smallest detail in my professional presentation. I could remember all too well the feeling of being not quite good enough in high school if I didn't have just the right outfit, and then put myself in the shoes of a young woman who could not afford to dress up to see a psychologist. I thought about all the subtleties of wardrobe which separate the "haves" from the "have nots". I thought about the kinds of clothes available to the young women who came to my office, afraid of being considered as outsiders or unacceptable yet again, and I made a conscious decision to change the way I dressed. I put away the expensive "power suits" and jewellry, and wore casual outfits. My wardrobe became simpler and less elaborate, and I made a conscious effort not to intimidate these young women by "outdressing" them.

I also made an effort to be genuinely welcoming. Offering coffee seemed like such a small thing, but I made a point of serving these women, rather than pointing them in the direction of the coffee pot, expecting them to serve themselves. We shared the small rituals of invitation and acceptance involved in making someone feel welcome, in the same way I would have welcomed an unfamiliar guest to my own home. By the simple act of offering coffee, I invited them into my office and they reciprocated by inviting me into their lives. With this and all the other seemingly inconsequential changes, I consciously stepped outside the way I had previously prescribed my role and became someone each client had not expected to meet. I was a person first,

and a psychologist, second. The conventional barriers between client and psychologist had disappeared, replaced by a tentative awareness of change that encouraged a new way of relating for each of us.

Exploring Equality

I thought about all the ways in which these young women were systematically excluded from sharing in the power which others wielded on their behalf. Depersonalized by the school system, social services agencies, and other professionals whose intentions were all for the best, Candy, Sharon, Grace, Wanda, Sherry, and Janice had clearly mastered the lessons of inequality. They were so certain of their place in the world, somewhere near the bottom and nowhere near the top, that they were extremely uncomfortable with the idea that change was possible. They desperately wanted reassurance that their lives could be different but had little sense of the personal power which could be harnessed to effect such differences. They wanted others to do the changing for them, so that if failure followed, as it inevitably would, it would not be their fault. They did not want to bear the burden of yet another mistake and inequality helped them avoid personal responsibility since every decision was made by others.

Because Sharon, Wanda, Janice, Candy, and Sherry had not been considered an intrinsic component of previous assessments, they had seen no reason to carry out the suggestions of other helping professionals. The process of clinical assessment was only something done to them, not done

for them. Their participation was mandated and involuntary. They were only there because they had to be, not because they thought they would gain from the experience. Within the boundaries of a traditional clinical assessment, their inability to follow through on recommendations was often labelled as yet another manifestation of the problems which had brought them to professional attention. They were identified as incorrigible, refusing to take the steps which had been outlined for them. There was no recognition that each had not been recognized as vital members of the decision-making process. These young women knew that they had been excluded. Armed with this knowledge, they had refused to cooperate.

In my involvement with each of these young women, I had to first acknowledge this unequal division of power. I knew, and they knew, that all the reins were held in my hands. Explaining the process of power sharing became a vital component throughout the assessment process, to ensure that each participant understood that the experience was as much for her as for me. Each needed to know that she was entitled, even encouraged, to have expectations about our professional relationship. She needed to know that she would be treated with respect, courtesy, and a sense of equality. Conveying this sense of shared power was vital to the change process for without it, the same patterns of learned helplessness would play themselves out forever.

CHAPTER NINE

Making the Suggestions for Change

This was the most difficult aspect of my work, this struggle to find new intervention techniques for the young women so clearly affected by FAS and FAE. I was painfully aware that there had been no shortage of other professionals who also thought they had had some, or perhaps all, of the answers. I wondered if I was merely deluding myself when I thought my interventions might make a difference. I knew that I could not change the underlying pathology which played itself out in so many aspects of these young women's lives but I also knew that I could not give up the fight to award them some small measure of dignity. There was no way to undo what had been done but I had made a commitment to each of these women, and they to me. We could only go forward, trying for new ways of being, groping our way together toward the changes which always seemed to hover out of reach.

In this search for new ways of offering assistance, I soon found that I needed not only my experiences as a clinical psychologist but also as a classroom and special educator, school counsellor/psychologist, and advocate for special needs children. One of these previous life experiences would not have been enough for these young women. They were greedy, these women who were so used to being left to their own devices, and demanded a level of knowledge that I was hard-pressed to meet. Before our contact, they had become resigned to the inevitability of their loneliness but

the possibility of a team approach made them respond in remarkable ways. Social workers would phone me and say, "What are you doing to Candy, or Sherry, or Janice? They want to come back and see you. How do you find out all that information? They've never told anyone that before. Do you have some sort of magic touch?" My response was always, "I just asked, and they told me". It sounded simplistic and it was, but it was honest and it worked. I did not assume. I did not pretend I had the answers before the questions were asked. I learned to wait, to listen, and to respect.

I gave each of these young women an opportunity to feel they belonged and had important contributions to make in planning for their futures. They had information and experiences that were vital to the process of intervention. Each of these women was an expert in her own life and all of the professionals, myself included, were the novices. We had things to learn from them. I merely informed them of that reality. To me, these women were indispensable. To others, they had been disposable.

In formulating possible interventions I initially focussed on education, perhaps because this was where it had all begun for these young women. School was often the first place they felt different. At school, they learned the lessons of "not good enough" and first felt the sting of rejection. We always began with questions about schooling. I found these carried a magical quality which unlocked the floodgates of remembering. Education could be counted on to elicit instaneous emotional responses. There was never any pretence when these young women recalled their schooling. The early

painful lessons had been too well learned.

Education

Each of these young women was singularly unsuccessful in her schooling. Special education programming bred resentment and oppositional behaviours, and firmly convinced each participant of her own inherent stupidity. When she was placed into regular classroom settings without support, she was just as convinced that there was something dreadfully wrong with her, but it still did not permit her to acknowledge her need for special education assistance and program modification. These women's educational experiences fostered anger, shame, and a sense of betrayal which laid an early foundation for their refusal to cooperate.

In examining their recollections of what it meant to be a student, I noted that, apart from these women's anger and disappointment, there was an underlying sense of powerlessness. They felt their opinions and their experiences did not matter. It was true they had refused to cooperate, especially in the junior and senior high school grades, but this seemed to be rooted in an attempt at preservation of personal control rather than in deliberate obstinacy. I wondered what might have happened if these young women, while they were still participants in the school system, had been given a voice in the planning process. What might have transpired if they had been made a member of an educational team, rather than the passive recipient of programming that made no sense to them? I had seen that,

when given an opportunity to participate in a process where they felt equal, they were more than willing to cooperate because they could see a reason for the suggestions which were made.

I wondered about the possibility of developing a team process for special needs students, especially in the junior and senior high school grades, where school personnel, each student, and support staff could discuss a range of programming options, presenting different alternatives in an atmosphere conducive to discussion. In my work with various school systems, I had learned that there was always more than one program to be considered, even though one might be more efficacious than another. I had also learned that students might be willing to work in one program, but not another, and their cooperation was crucial to the end result. Foisting an unwanted program on a student old enough to quit was a sure way to ensure his or her early leaving. I did not want to be so cynical as to think that some of the programming suggestions for these young women had been made with that unspoken goal in mind, but I knew that, as students, they had been difficult to teach and discipline. These young women were seen as angry, stubborn, and occasionally violent and it would have been no surprise if teachers and administrators breathed a collective sigh of relief when they left school. I, however, saw their anger and refusal differently. To me, it seemed to stem from a sense that this was the one of the few ways they could communicate their feelings to those in positions of power. By giving these young women a legitimate place in the process, it might have been easier to anticipate and defuse the rage which overwhelmed them and frightened off

the others.

From their memories as students in the elementary grades, these young women were paralyzed by their problems with peers. Not one could recall the name of a childhood friend. As children they were alone, without the social skills to participate in the daily interactions which take place in each classroom. They remembered how their special needs served to further isolate them, giving other more capable children additional ammunition in playground skirmishes. They withdrew, unable to reach out to embrace learning, because they could not see themselves as valuable contributors to the overall environment. Again, I wondered what might have happened if each child had been made to feel an important part of her classroom.

From my own experiences as an elementary school teacher and school counsellor, I knew about social skills training, programs which stressed self-awareness and empathy, sharing circles, individual conferences, classroom discussions, and role playing, all of which could be used to develop a more inclusive classroom environment. I felt confident that some of these would have worked well for these young women and for all the other students who did not quite fit in.

I began to think about how I could help educators realize their impact on these children, and their potential to show caring, through even the smallest gesture. I also was well aware of the stresses placed on teachers to do more than they could in the time allotted each day. I formulated a list of

simple, concrete recommendations, stripped to the bare bones so that overtaxed teachers would not see this as simply one more burden to add to a day crowded with so many other essentials. I made it a "do" list rather than a "do not" list. Teachers already get too many messages telling them what they shouldn't try, but far too few telling them what they should.

Interventions for Elementary School FAS-FAE Students

1. For children identified with FAS and FAE at the elementary level, institute a structured program for social skills development. Teach the missing skills in a sequential fashion, offering opportunities to practice kindness and sharing.

2. Celebrate small acts of inclusion and the strengths of each student.

3. Create a classroom atmosphere where differences are not a mark of shame.

4. Praise each student every day, even when you think you can't.

5. Be kind, especially when you do not want to be, for these are children who have so few memories of compassion.

6. Ignore as best you can the annoyances of inattention, lack of concentration, distractibility, and motor overactivity. These children

cannot curb their fidgety, restless behaviour. They do not wander to annoy, they do it because they cannot stop themselves.

7. Encourage the sharing of school snacks between students or, if you feel comfortable with this, bring food from home because you might be the only person to feed this child.

8. Unobtrusively make clothes from the school's "Lost and Found" available if you notice a child coming to school in the same dirty outfit, day after day. She does not want to be unclean but may not have the money, equipment, or training to do her own laundry.

9. Report suspicious bruises, welts, burns, scrapes, and other marks of physical injury to the proper authorities. You might be the only person to see this child on a regular basis and you might be the only one to stand between safety and physical abuse.

10. As a teacher, you will make a difference in this child's life. You can be an adult like most of the other adults she knows, who are deliberately cruel or neglectful, easily frustrated, or too busy to care. But, you can also be an adult different from all the others, who is kind, accepting, and tolerant. The choice is yours.

Interventions for Older Students with FAS/FAE

For the older students with FAS or FAE, those in the troubled years of junior and senior high school, the recommendations included all of the above, as well as others specifically for older children.

1. Be aware these students are struggling with issues of personal safety, drug use, problematic sexual behaviours, poverty, and family violence. Do not be surprised if some of these same behaviours appear in your classroom.

2. Do not be resentful if students appear uninvolved in your carefully-prepared lessons. Your classroom might provide them the only place where they feel safe enough to sleep.

3. Refer students who seem especially withdrawn, depressed or explosive to the school counsellor. Do not assume that someone else has done that. Be the one who cares enough to intervene.

4. Request a comprehensive psychological assessment for students who are having academic difficulties and ask that you and the student be included in the debriefing.

5. Make yourself available to listen for you can accomplish much by your physical presence.

6. Do not be frightened by these young adults. They are more angry at themselves than they are at you.

7. Greet each student by name. This will help them feel less invisible.

8. Find something positive about each troubled student, even if it means that you acknowledge her as the best "worst kid" you've ever known.

9. Be structured in your teaching. These young adults cannot provide their own internal organization to cope with the chaos of a busy classroom.

10. Do not be surprised if homework is not done; the student may have no quiet place to work at home, or no home in which to work.

11. Take a stand against bullying in your classroom and in your school. These students cannot defend themselves against the verbal jabs of their peers and, if they do not act out physically, their only other defence is to run.

12. Give students time to express themselves verbally.

13. Be prepared to explain things again, in simpler language. And then, be prepared to explain things again.

14. Provide copies of your notes or overhead acetates because these students cannot copy information down quickly and accurately.

15. Some of your students may be homeless. Assume that a student who shows up unclean and wearing the same clothes day after day is not doing this to be annoying. Be prepared to ask for assistance from the school counsellor, social worker, or police liaison officer on their behalf.

16. Expect to be frustrated, angry, and unhappy with these students. It is the way they live and they do not have the skills to change for you, even if they wanted to.

17. Expect to be saddened by these students. Underneath their "street smarts" and bravado are often frightened and directionless children who desperately want to be loved.

Families

I also wondered about the families of these young women. Nothing could be done to help the parents of Janice, Candy, or Wanda or to give them the tools to change their own ways of functioning. These strategies had been advanced before although never accepted and it was too late for the interventions which might have changed these young women's stories. There were other parents, however, who would not have rejected assistance offered. In the supportive, caring adoptive or foster families which had taken

children like these and like Sharon and Grace into their hearts, I knew that there was the possibility of awareness, growth, and empowerment. These families had wrestled with feelings of guilt, despair, desperation, and rage at the burdens which had been handed to them. They loved their children, but did not know how to explain the multiplicity of their needs to the strangers or professionals who did not understand the problems they lived with each day. These parents grew angry at the world, and then angry at these children who caused them such pain. And finally they grew angry with themselves, hiding their burdens of self-loathing and guilt like shameful secrets.

These families had developed a saving emotional numbness from holding all the hurts inside. They had been disappointed so many times that they no longer knew how to advance hope for the children they had accepted with such dreams. They, who had taken responsibility for these children with such optimism and such a lack of knowledge, were always surprised by the inevitable disappointments which accompanied their lack of preparation. While they never denied the disappointments, they were nevertheless surprised by the depths of their frustration and sorrow when all the early dreams went unrealized. These familes learned to develop a survivor's outlook, laughing away the pain of continual frustration and sorrow. They learned not to look too deep inside themselves and cultivated the social graces which kept others from realizing the depths of their despair.

Along with the despair came exhaustion. Grace and Sharon's families were worn out by their struggles to parent, educate, and advocate for their

children. They had been hampered from the beginning by their lack of knowledge although they had acquired an education the hard way while helplessly watching their daughters fail. They knew something was wrong but they did not know what. They asked questions and demanded answers but there was no one who could give them what they wanted. Placement social workers had retired. Files were closed. Information was inaccessible. The teachers or other professionals they initially consulted did not know about FAS or FAE. The parents often found themselves in the position of educating those whom they had hoped would provide information for them. The research they found was too often limited to dry statistical analyses of FAS and FAE which bore little resemblance to the reality they lived each day. With the exception of Dorris' book which documented his struggles with his own FAS-diagnosed child, there was no professional literature they could use to give weight to their words. These parents were truly alone. The traditional sources of support they relied upon could not meet their needs.

In desperation, they organized parent support groups. These were a way for the participating families to acknowledge the difficulties they had faced and to share what little knowledge they had gleaned along the way. They passed along the names of sympathetic social workers, psychologists, teachers, lawyers, or judges. They developed a network of support which they used in their battles with various groups, agencies, school systems, or the other bureaucracies which sought to deny their children their due. While they were powerless to change the underlying organicity which had caused their childrens' problems, they refused to stand idly by and wait for others to

point the fingers which would only reinforce their own sense of shame.

These parents organized, petitioned, and agitated for their children. They laughed, wept, and comforted each another. They listened to each other's stories with acceptance and compassion. They did not judge, even when one of their members revealed in a group meeting that she had given birth to a FAS-diagnosed child who had then born four other FAS-affected children which she was now raising on her own. There was no condemnation from the other parents towards this bewildered grandmother. There was no time for this in their lives. They were focussed on change, not on assigning blame. Each family had already experienced enough of this from those outside the group to think of casting aspersions on their fellow sufferers.

An inevitable consequence of support group membership was a gradual thinning of the ranks as older members dropped out and were not replaced by new members with the energy to sustain the group. Organizers and leaders moved, or burned out, or lost their children to the justice system and gave up. Support groups were only as strong as their most determined members, who could not sustain the momentum necessary to simultaneously run a voluntary organization and parent their FAS-affected child or children. They were ephemeral sources of support without official recognition and without the power to effect change. Although they had hoped that they could raise professional awareness by combining their voices, most support groups vanished before they could realize their goal of advocacy and a greater

public profile. Once again, advocacy became a personal struggle, exacting a powerful toll on the families which bore their burdens alone.

I knew that I could teach these families little. They had more knowledge, gained more painfully, than I could ever comprehend. And so I learned to wait for their instructions much as I had waited for their children to set the pace. They had no need of experts. They all bore the scars of meeting with those who claimed to have all the answers but who never waited long enough to hear the questions. With weary dignity, these parents expected me to listen rather than to speak; to learn rather than to teach.

Poverty, Unemployment, and Prostitution

The issues of poverty, unemployment, and prostitution were more difficult to address since they were dependent on political intervention. Little could be done to address these areas, since I did not have the power to secure more money for these young women, or find them jobs so that they could earn the money to keep themselves out of poverty and away from the streets where they earned their living the only way they knew how. I did not have the resources to provide easier access to emergency or subsidised housing, practical job-training programs, or the various food distribution centres scattered throughout the city. These were difficulties I could not solve. What I could do, however, was to give these young women a vehicle to share their needs with the larger community, letting them tell their own stories in their own words. Perhaps their words will be listened to, when all the others

have failed.

Health Issues and Pregnancy

Each of these young women struggled with chronic ill-health, some of it surely self-induced, but some related to years of neglect and to the physiological manifestations of FAS and FAE. They had no one to turn to, when they had questions about their own bodies, and their level of general knowledge about issues such as birth control, sexually transmitted diseases, and prenatal care was appalling. These women, so used to drifting along in the shadows, did not know how to access consistent health care. One of my responsibilities became finding a supportive health care professional who could work with them and take the time to correct their misconceptions. For these young women, unable to ask for the assistance they so surely needed, I became a referral source. I made sure that their social workers also knew about their need for adequate medical care because I could not ensure that these women would keep the appointments made for them. They forgot the time, or the date, or the address, or the physician's name. Although they wanted to be healthy, they didn't know what that felt like. As individuals who alleviated personal stress through somatic complaints, the thought of feeling good was threatening. If they had no aches and pains, they might have to look at the bigger issues which were masked by the headaches, back aches, and gastrointestinal problems which they used as a crutch to get through each day. These young women had a vested interest in ill-health. It had become an excuse to remain where they were. If they were too sick to

change, then staying in the same dysfunctional situation was acceptable.

Emotional Functioning

These young women were all in great need of personal and professional support. Their coping skills were highly problematic and inappropriate, exacerbating underlying pathology and creating further psychological dysfunction. They used street drugs and alcohol in an attempt to self-medicate, usually with disastrous results. They misused prescription medications, reasoning that if one anti-depressant was good, then four or five washed down with a beer would be even better. They desperately needed intensive therapy but did not know how to access the limited services available to individuals without the means to pay.

Most psychotherapy or counselling techniques were inappropriate for these young women. They were struck dumb in the face of traditional therapeutic approaches; rendered voiceless by the stress placed on linguistic competence. They were more successful in directive, action-oriented therapeutic approaches; finding the linguistic demands of traditional counselling or psychotherapy too much to manage. They also could not bear the stresses which were thrust upon them in group counselling situations. They, who could not manage the intracacies of everyday social interaction, were paralyzed in support groups. They were accused of being uncooperative, of sabotaging group process, or of being unable to relate to other group members. In defense of the group leaders who struggled

valiantly to lead them to greater personal awareness, these young women likely were all of those things, but none of them had chosen this path deliberately. Their problems with social functioning were not dropped off at the group therapy door, to be donned again when the hour-long session was up. For all their faults within group treatment settings, they remained true to themselves. They did not change for anyone because they did not know how. And so, despite my best intentions, I was often unable to find a suitable therapeutic environment which could cope with their special needs. There was no one to work with these young women, and no one to pay.

As many of these young women were being supported by Social Assistance benefits, they did not have the luxury of paying for therapy from a psychologist or counsellor in private practice. Although these were the professionals who usually had more flexible schedules and therefore could provide more immediate support, they remained inaccessible because of these women's inability to cover the fees. These young women could not pay and therefore they were often referred to the low-cost or free mental health services offered through government agencies or non-profit services. Although professionals at these agencies were less expensive, access to them was limited, because of the increasing demand for their services. There were long waiting lists to see a psychiatrist nurse, and if one needed to see a psychiatrist, the line-up was even longer. If one of these young women was able to follow through on my suggestion to arrange a psychiatric consultation through a sympathetic personal physician, the waiting period was longer yet. By the time one of these young women might get an appointment date, she

might have moved again, or forgotten why she had wanted help in the first place.

Isolation

This was one of the themes which underlay all the others. Illiteracy, poverty, unemployment, prostitution, ill health, pregnancy, problematic emotional functioning, and suicide were each magnified by an incredible sense of isolation. These young women were truly alone. They had no supports or connection to their community; the only constants in their lives the social workers who were too busy to care. For a very short while, I was there, but my contact was as tenuous as any. I was not mandated to contact them, once the assessment process was completed. I could not make them keep in touch and so we drifted apart.

I had a selfish dream for these young women who presented themselves in my office; defiantly, ignorantly brave despite their many setbacks. I knew that I could not effectively advocate for them because I did not have the time or the energy to coordinate all of the extra resources each woman needed. I knew that this was a much larger job than one person, even with the best of intentions, could manage. I also knew that I would be unable to maintain the pace these women demanded and I would too soon become exhausted or hardened, and like so many of the others who no could no longer endure the never-ending struggle. And so, selfishly, I contemplated an alternative which might give me back a few precious moments of time and

which would also give these young women the support they needed.

When I began working with this population of young women, I had often thought I would be more effective if I had four more sets of hands and the energy to go with these extra limbs. While I could not grow more arms, I could find others who might lend me the strength and determination of their hands. This was a struggle bigger than any one person could maintain. I knew that there might be others who could give the young women like Candy, Janice, and Sherry access to those other arms with their attendant power.

In thinking of how this load could be shared, I wondered about the possibility of establishing a drop-in centre for marginalized young women where these and other troubled adolescents could find the support and referral services they needed to function more appropriately. There were other centres for youth in the city, but they often had a specific focus, such as employment, storefront education, or shelter from abuse. They were also open to male and female adolescents, leaving these young women vulnerable to continued abuse and exploitation from the young and not-so-young men who preyed on girls such as themselves and who found such programs excellent recruitment centres. In our city, there was no umbrella organization established to work with young women who presented with needs across a wide spectrum. Although some of the other centres did try to address more of their clients' needs than they were mandated to do, they simply did not have the resources or the time to coordinate the highly individualized support these young women required.

I speculated that a centre such as the one I proposed would likely be expensive to operate and dependent on funding from various arms of civic, provincial, and federal governments, but could provide the comprehensive support these young women needed. It would also give these young women, so unable to ask for help on their own behalf, a "one stop shopping concept" where they would not have to go over the details of their lives again and again. Instead, on registration, each would be assigned to a personal support staff who would be responsible for gathering a detailed history and then accessing the appropriate members of a multi-disciplinary intervention team. Health professionals, such as a physician or nurse-practitioner, could provide information on basic health issues, birth control, prenatal care, and sexually transmitted diseases, dispense medications, monitor chronic health problems, and refer to appropriate medical specialists. Drug and alcohol counsellors could also be available on-site, providing information on detoxification programs, assessing an individual's need for various levels of support, and running self-help groups. Adult educators could run individualized literacy training, coordinate volunteer literacy workers to work with individuals or small groups, and provide information on academic upgrading or other community-based literacy programs. Trained counsellors could run support groups, provide drop-in emergency mental health care, or refer to psychiatrists or psychologists as necessary. Employment counsellors skilled in working with youth could also work on-site, helping those capable of training for employment to access existing programs or fill out the endless forms necessary to receive training allowances to permit a return to school. On-site social workers could assist young women with childcare issues,

parenting strategies, or determine the need for further intervention from various government agencies.

Despite the desperate need I had seen in these young women, the probability of such a centre developing seemed slim. Although the marginalized participants in this exploration were unable to access the few resources currently available, they might never take their first steps toward personal change if they were forced to do it alone. For too many of them, there was no one to stand beside them and show them the possibility of a different way of being. They had no families to help them, or the families they had did not want to acknowledge their role in keeping their daughters dependent and dysfunctional. Only the lucky few, like Sharon and Grace, knew there was another way to live. But, if the other young women like Candy, Wanda, Janice, and Sherry knew there was a place to go where they could be understood and heard, it might go a long way towards alleviating the isolation which kept them so firmly in their places.

CHAPTER 10

Implications for Further Inquiry

In my search of the literature on Fetal Alcohol Syndrome and Fetal Alcohol Effect, I noted the abundance of empirically-based scholarly work. Quantitative researchers had done much to document and verify the presence of this syndrome and clearly described its physical, educational, emotional, and social characteristics, especially in populations under the age of twelve. Little was known, however, about the effects of FAS and FAE in older individuals and there was a clear need to examine how this syndrome affected adolescents and adults. The children first diagnosed with FAS or FAE had grown into adults, but research had not kept pace. An emphasis on older populations with this syndrome could do much to provide those working in this rapidly-developing field with additional information.

The limited research on maturing populations with FAS and FAE was restricted to empirical data, valuable but nevertheless not reflective of the day-to-day lives of the young people I worked with on an ever-increasing basis. There was so little of the desperate beauty and inarticulate dignity of these young women. There was no portrayal of the quiet strength, dogged determination, and stubbornness which kept them moving on. The lives of Grace, Candy, Wanda, Sherry, Janice, and Sharon were not represented by the scholarly work I examined. They had somehow been lost; falling between

the rows of statistical tables into a limbo of terminology which made no place for their own stumbling words. They had been reduced to numbers on a chart. Their overwhelming weaknesses obliterated their few strengths until one only saw the failures and lost sight of the tiny triumphs which blazed so valiantly small against the overwhelming darkness of each life.

I knew that the traditional methods of research would not do justice to these young women. Their stories compelled me past the detachment of my traditional training to somehow touch the very heart of who I was as a practictioner of clinical psychology. In the presence of their voicelessness, I was forced to evaluate how I used language and how it served to separate the articulate from those whose words were judged to be imperfect. I was confronted by my own assumptions about worth and dignity, made to look past the superficialities into the places where I had not looked before. I was being moved to a new way of knowing, a new way to hear what was said and what was silent. As a clinician-researcher, I knew I had to paint a picture, using these young women's words and my own, of the value in examining and then moving past the prejudgments, the prejudices, to a different way of being.

In my attempts to understand how the lives of these young women had resonated so strongly with my own, there was a selfish desire to delineate, and by so doing, understand the process of change which I had undergone. There was also a less selfish wish to open the field of psychology towards new ways of understanding and exploring. The introspective nature of

qualitative research brings a new dimension to the field of psychology, providing a forum for the development of new awarenesses, understandings, and uncoverings. Qualitative research encourages clinicians in the field to explore their own competencies, to find what works for them and why, and to come to a level of understanding about the interactions between the clinician/researcher and the client. Qualitative research, with its emphasis on narrative and the human voice, can have a profound influence on practice. The stories of other clinician/researchers provide a way of knowing connected to the "... political context of story and the issues of gender, power, ownership, and voice captured...by a narrative framework" (Carter, 1993, p. 3). Other clinician/researchers are encouraged to explore this way of seeing; to look at other issues, or to look at familiar issues with new eyes.

I began this journey into the lives of young women with FAS or FAE with the view that I would uncover new understandings about how they lived their lives but found more than I had bargained for. I learned that there is still much I do not know, not only about these young women and all the others like them, but also about other individuals who have been marginalized and rendered voiceless. There are so many groups whose presences have not been valued; the poor, the homeless, the chronically unemployed, the street kids who inhabit the dumpsters and parkades of our cities, the drug and alcohol-addicted, and the prostitutes all have something to contribute our understanding of ourselves and the society in which we live. Scholarly research can include their stories as well as anyone's.

In my work with these young women, I found that there was no benefit to asking them a multitude of questions. They became overwhelmed with my words, forgetting their own in their struggle to tell me what they thought I wanted to hear. They wanted so desperately to please me, that formalised questions became a hindrance rather than a help. I learned that letting them choose where our conversations were to go was more reflective of the true nature of "story" than were my attempts to manipulate the process. I discovered the freedom inherent in letting go of the control I had struggled so hard to gain. I no longer needed to be the one in charge and, in the letting go, I became free of the constraints of role and power which had bound me into a way of being to which I no longer subscribed.

I found that there were areas where I could not go, within the time restraints of this exploration. I could not look at the apparent differences between the lives of men and women with FAS or FAE. I could not explore the ramifications of rural versus urban experiences in FAS and FAE-affected women. I could not follow them through the routines of their day and watch the little interactions they might have not thought important enough to tell me. I could not follow each of these women for more than one to two years. They were too transient, too difficult to find once our initial contact had ceased. I still wonder about each of them, though, and look for them in places where they used to be. With the exception of Grace and Sherry, most have not kept up the tentative bonds of friendship we made. I do not fault them for this. Their lives are far busier than mine; filled with problems that I still do not understand. I am grateful for what we shared and for the truths they helped

me see. At that earlier stage, when I was in closer contact with each participant, I thanked each for her time but I did not thank her for her wisdom. This was not a deliberate oversight, because I only learned what she had to teach me in retrospect. I learned by doing something each of those young women had not yet mastered - the art of looking back to see what had gone before. So now, with this work I would like to do what I could not then. I thank each of them for their patience, their understanding, and their knowledge. They have taught me much and I will not forget them.

EPILOGUE

I wondered about what could be done for these young women, who had so many disadvantages, so many experiences of failure, and an underlying pathology which confounded even the best-intentioned of professionals. I wondered how I dared to think I might be successful, where so many others had failed. Results of previous assessments had clearly outlined what was to be done but nothing substantial had ever transpired, as far as I could determine. These young women with FAS and FAE had confounded most of the other helping professionals who had been involved in the past, and I had no guarantee that my suggestions would be any more practical or suitable for implementation. I knew that I could not alter the combination of central nervous system dysfunction, physical health problems, underlying language and communication disorders, diminished cognitive functioning and mental handicap, and extreme social isolation which cohabited in uneasy alliance in these young women. I could not go back and undo the damage which had been done to them, before they even drew their first breaths. I could only paint pictures of their lives, using my words in partnership with theirs, for the others who did not even know that these young women existed. I wanted to show all those who thought that FAS and FAE were problems for other communities but not for ours, that we were all vulnerable. I wanted the doubters to witness the reality of this disorder first-hand, from the very mouths of those who bore undeniable witness to the effects of maternal alcohol consumption.

There were so many commonalities in the lives of these young women affected by FAS and FAE. Continued failure in education, employment, and social functioning was ever-present. Emotional and psychological dysfunction, suicide, poverty and its attendant problems of health, poor nutrition, and powerlessness, an unending cycle of pregnancy, and sexual abuse were identified in most of these young lives. But, underneath this pattern of dysfunction, lay the threads of isolation, inequality, and voicelessness which bound the other aspects into a recognisable garment each young woman wore like Joseph's cloak of many colours.

It was sometimes so very difficult to find the woman underneath the patchwork of impairments; a painstaking process, this unwrapping of multi-layered dysfunction to uncover the person inside. It was not unlike that old Christmas present trick, where progressively smaller boxes are wrapped and then nestled each inside the other, concealing a tiny but precious gift found only after mounds of brightly coloured paper are torn away and discarded. It felt very much like that, searching for that final tiny box which cradled each person, free of the other boxes which had held captive who she really was.

In this unwrapping process called research, I learned that many of the practices to which I had once so vigorously subscribed were no longer helpful. These were the nested boxes, the clinical assumptions which simultaneously described and restricted each woman. She was ultimately all of those things but yet none of them. More than just the embodiment of a clinical syndrome, each young woman had a particular dignity which kept me

looking through the boxes, searching for who she really might be.

Grace, Sherry, Janice, Candy, Wanda, and Sharon, the women inside the boxes, revealed that individuals with limited intellectual functioning and extremely concrete language skills, as determined by the measures we traditionally use to assess educational and social success, could be eloquent spokespersons. Through each of these women, I learned that others who are similarly affected might also have valuable information to impart, although they may not say it in a fashion we are accustomed to hearing. I learned that we, all the "others" who provide services or seek to help, need to accept them as they are, listen to what they can tell us, and be prepared to offer no judgement or condemnation. We need to listen to the voiceless among us; the women who do not seem to learn the lessons necessary for survival. We need to understand the reality that Grace, Wanda, Candy, Sherry, Janice, and Sharon live each day. They did not ask to live this existence, coping with a life more complicated that they can manage unaided. We should not let them live this life alone.

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APPENDIX A

Semi-Structured Clinical Interview

Semi-Structured Interview

Ask about school history

Specifically query possible learning disabilities, previous testing or special education classes, problems with attention/concentration, motor restlessness or overactivity, distractibility.

Ask about educational transience.

Ask about individual's recollections of herself as learner.

Ask about positive and negative recollections of school.

Ask if there were significant individuals whom they can remember as making an impact on their educational progress or on their perceptions of self as learner.

Ask about employment history

Specifically query if individual has been competitively employed, the duration of employment, reason(s) given for termination.

Ask if the individual has been declared competitively unemployable.

Ask about early home life

Specifically query about family behaviour, transience, possible foster placement/Social Services involvement/adoption and the reasons for this.

Specifically query about possible family dysfunction, including physical, emotional, sexual abuse issues.

Ask questions about health history

Specifically ask about cardiac functioning, premature birth history, problems

with respiratory functioning, seizures, scoliosis, muscle problems.
Specifically ask about accidental injuries, especially those sustained as a result of impulsive behaviour and/or motor vehicle accidents.
Ask about periods of hospitalization.

Ask about adaptive behaviour

Specifically query any problems with impulsive-type behaviours such as shoplifting, difficulties with anger management, substance/alcohol abuse.
Specifically query whether individual has done jail time and if so, what for.
Specifically query whether individual has lived on the streets, has had difficulty establishing stable relationships, or has moved in with others simply because she has been unable to cope with independent living.
Specifically ask if individual has difficulty making decisions or problem solving.

Ask about emotional functioning

Specifically query if individual has difficulty with depression, anxiety, obsessive or phobic behaviours, low self-esteem.
Ask if individual has been hospitalized for psychiatric disorders.
Ask if individual has a history of suicidal ideation, gestures, or attempts.

Coping Strategies

Ask if individual uses any particular coping strategies in her day-to-day life.
Ask which ones are successful and which ones are not.

APPENDIX B

Unstructured Interview

Unstructured Interview

Background Information

What has been important for you in your life over the past few months or years?

Tell me something about what your life is like right now.

What do you care about?

What do you think about?

Self-Awareness

How would you describe yourself?

If you were to tell yourself who you really are, how would you do that?

Is the way you see yourself now different from the way you saw yourself in the past?

What led to the changes?

Have there been any important events which helped you to change?

How do you see yourself changing in the future?

Gender Issues

What does it mean to you to be a woman?

Have you seen any important differences between the ways men and women are treated?

Tell me some of the ways that being a woman has changed for you?

Relationships

Looking back over your life, what relationships have been really important to you? Why?

How would you describe those relationships?

How would you describe your mother (or primary caregiver)? Your father?

Has your view of your parents changed over the years?

How would you describe your child/children?

Tell me if you would like your children to have the same experiences you did.

Coping with Dilemmas

Everyone has found herself or himself in a situation where they had to make a decision but they weren't sure what was the right thing to do. Could you tell me about a time when you had to make such a decision, where you didn't know if you were doing the right thing?

What was the situation? How did you feel?

In trying to decide what to do, what did you think about? Why? Were there other things you thought about when you were trying to decide what to do?

How did you decide which way was the best way for you?

What did you decide to do? Why? What happened?

Looking back on this now, do you think you made the best choice? Why or why not?

Looking back, what do you think you learned from this?

What would you tell someone else in a similar situation? Would it be different from what you did?

Intervention Strategies

When you talked about your childhood and adolescence, you mentioned some difficult times. What kind of help do you think you needed to get through these difficulties?

Sometimes when children or adults have problems they try to get help. What did you do to get help? Tell me what happened.

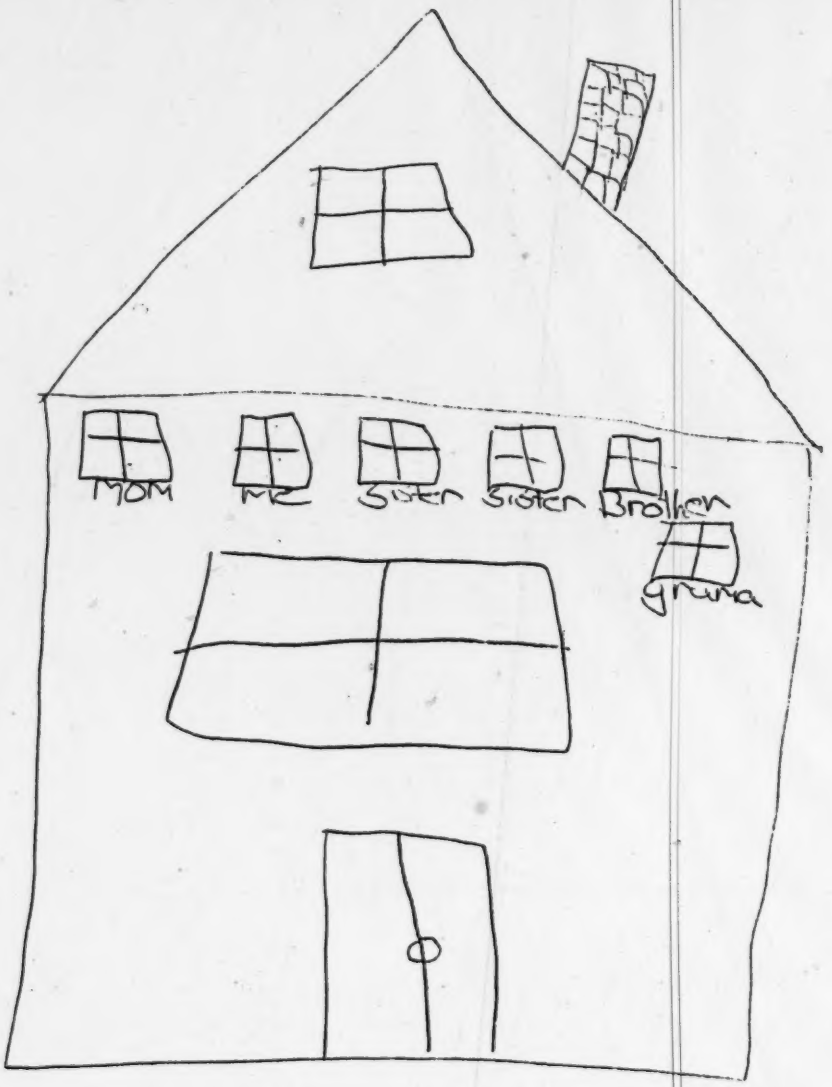
Since you have been through these difficulties, tell me of some ways that might help other children or women who are having similar problems.

Tell me what has been helpful to you as you have grown up.

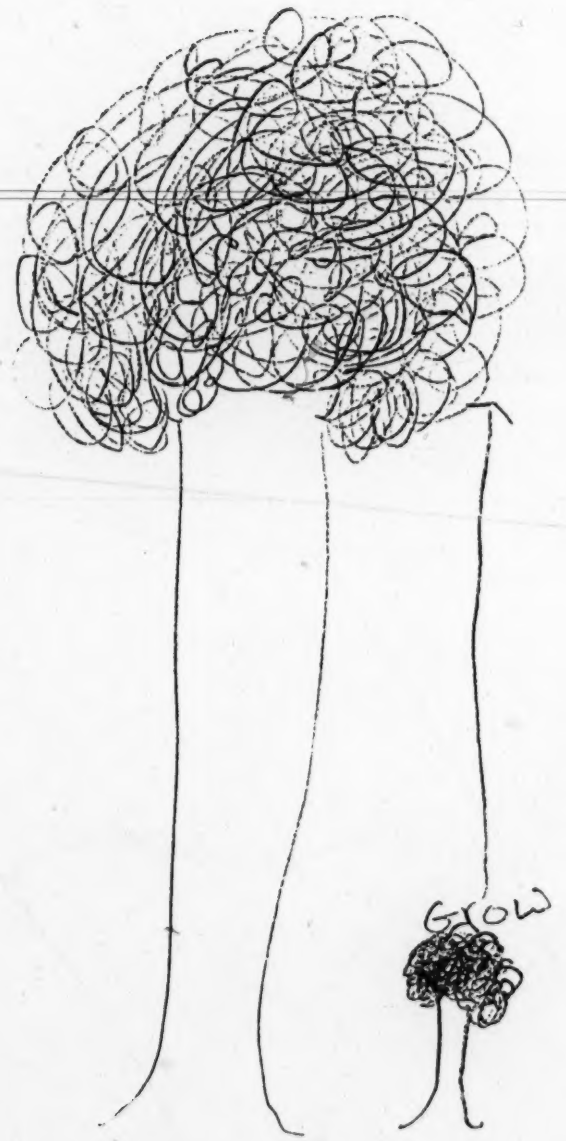
What has not been helpful to you?

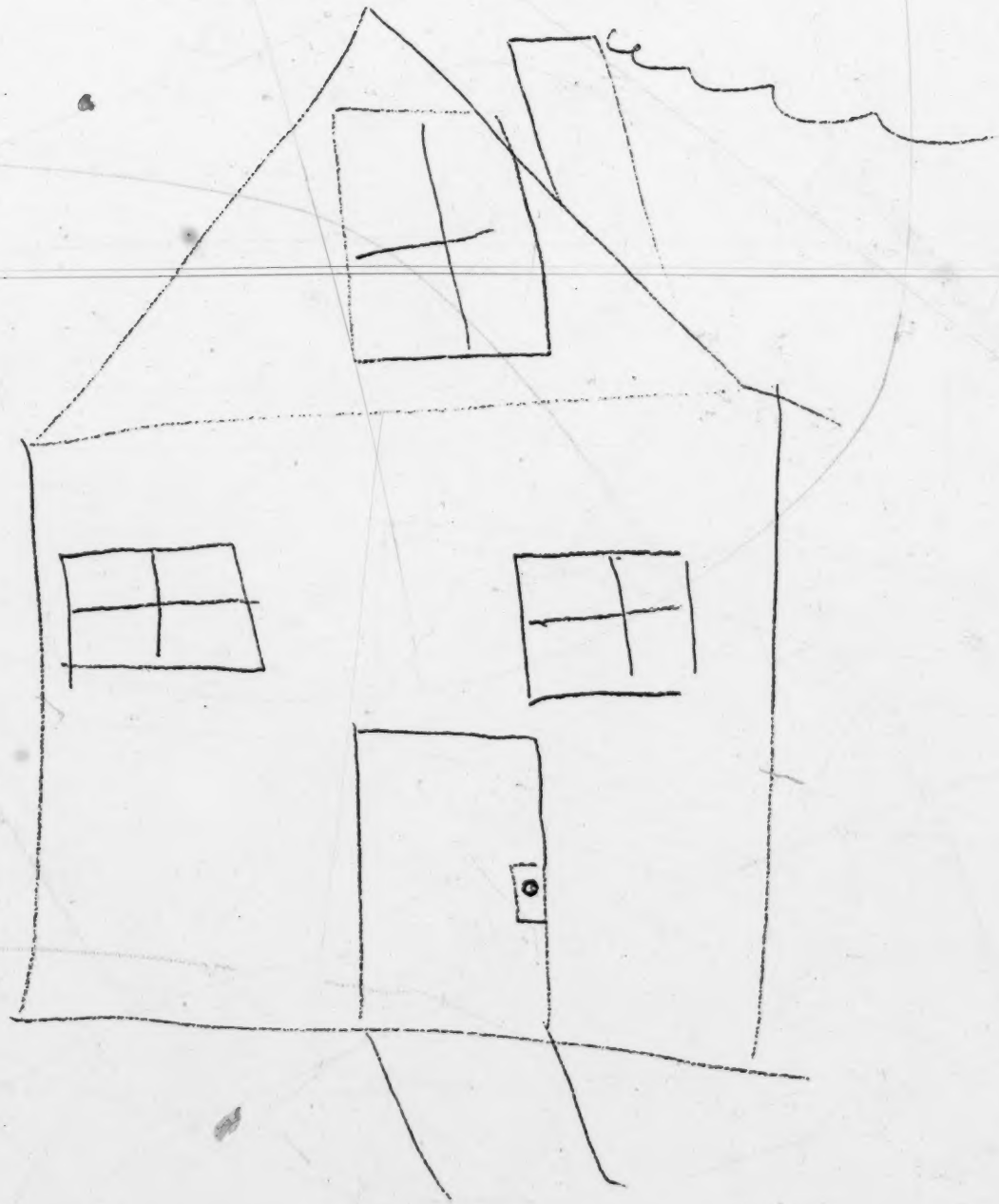
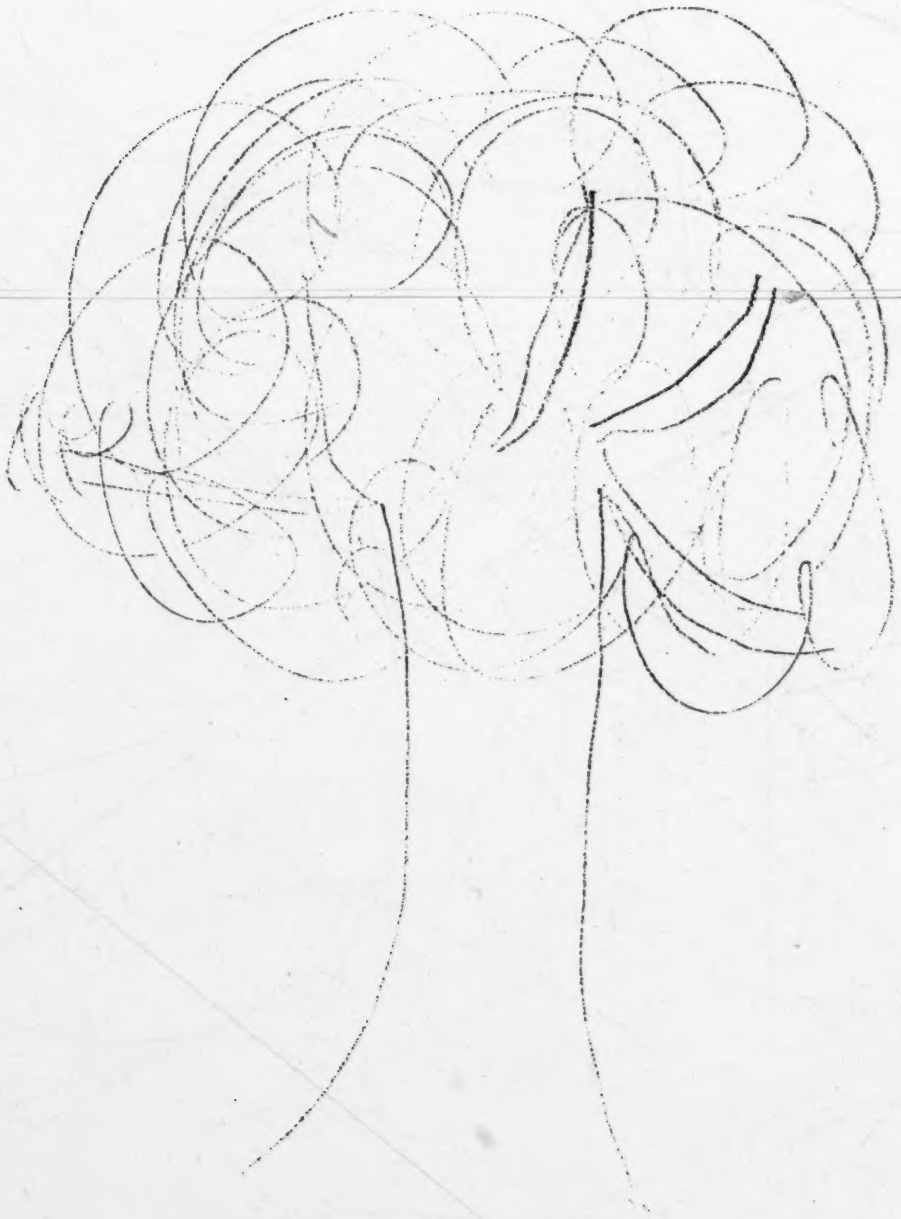
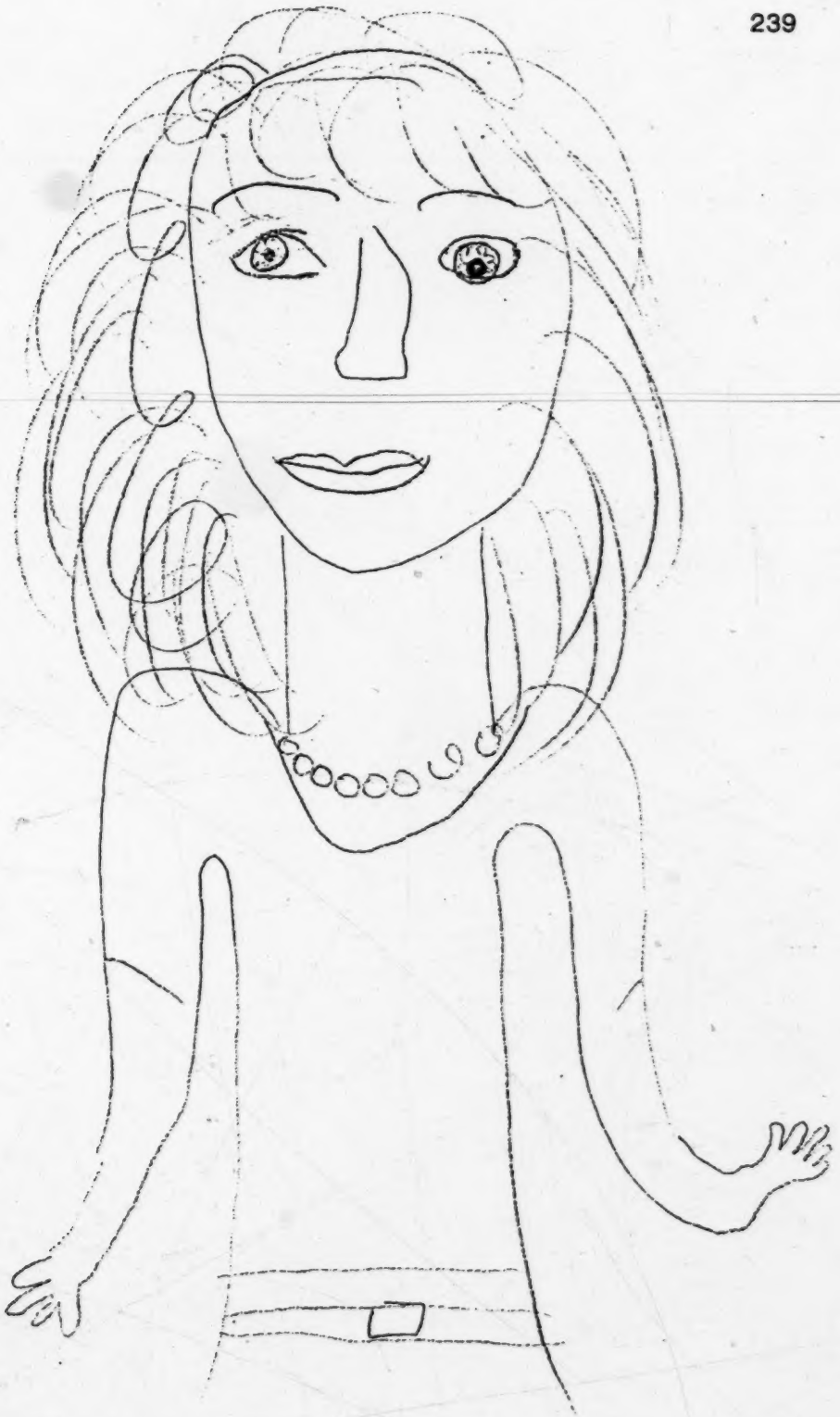
APPENDIX C

Participants' Drawings



doghouse.
sorry Mek.


GROW

I really Like But that is ok that you ~~can't~~ cannot be my mom. But we can always be friends for life right.

I want to go home with my Daycare and Yellowhead Youth centre and home to mom Because right now I am feeling sad. and mad.